Disability and Difference: The experiences of South Asian disabled children, young people and their parents and their access to services

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A Doctoral Thesis

submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy

De Montfort University

April 2005

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Abbreviations

ABA	Association of Blind Asians
BME	Black and Minority Ethnic
CIO	Confederation of Indian Organisation
CRE	Commission for Racial Equality
CSR	Critical Social Research
DDA 1995	Disability Discrimination Act 1995
DfEE	Department for Education and Employment
DfES	Department for Education and Skills
DoH	Department of Health
DRC	Disability Rights Commission
EOC	Equal Opportunities Commission
IRT	Identification Referral and Tracking
RNIB	Royal National Institute for the Blind
RR (A) Act 2000	Race Relations (Amendment) Act 2000
SCD	Sickle Cell Disorder(s)
SEN	Special Educational Needs
SENDA 2001	Special Education Needs and Disability Act 2001
Skill	National Bureau for Students with Disabilities
Social Model	Social Model of Disability
TSO	The Stationary Office
UNCRC	United Nations Convention on the Rights of the Child
UNHCHR	United Nations High Commission For Human Rights

Acknowledgements

I would like to thank the many people who supported me in conducting this study. It is impossible to name them all, however, I would particularly like to thank the following:

The South Asian disabled children/young people, the South Asian parents, and the service providers for their participation. I am grateful to both the parents for their involvement and the service providers for their support with informing the parents on their database about the study.

George Taylor and Hazel Kemshall (my supervisors) for their motivation, guidance and expertise, which was very much appreciated.

De Montfort University for the award, which made it possible to conduct this study, and the staff at the Research Unit for their advice on meeting the University's regulations and procedures.

Sue Johnson and colleagues at the Royal National Institute for the Blind.

Robert Orr (consultant) for advice regarding data collection with children with multiple disabilities, including complex needs.

Chris Bush at the Multi-Agency Disabled Children's Services Co-ordination Project (Leicester City Council) for his understanding, advice and support which helped me to complete this study.

Alison Skinner for proofreading the thesis and offering advice, which improved my writing skills. Sarah Ellix for proof-reading the final thesis.

Friends and colleagues, in particular: Ansuya Bhakta, Bud Simpkin, Julie Fish, David Batchelor, James Palfreman-Kay, Jo Aubrey, Laxmi Patel, Bhanu Mistry, Jenny McMillan, Pratibha Mistry, Jo Drury, Julie Kent, Paul Weston, Bob Broad, Mark Johnson, Ronny Flynn and colleagues at the Adult Planning Section (Leicester City Council) for their support and encouragement.

Meg Jones for advice about a range of issues, endless hours of counselling and helping with the proof-reading. Caroline Law for assisting with the young people's summary.

Margaret Hill, Teresa Selby, George Taylor, Chris Bush, Angela Reynolds, Meg Jones and Tikka Patel for assisting with the fun morning and group meeting.

Angela and John Reynolds for their friendship and support with my many requests for assistance, and John's prompt response to my numerous computer related queries and proofreading the thesis which is much appreciated.

My family particularly Jim for living with me during this thesis.

Abstract

This qualitative study examines the experiences of South Asian disabled children/young people and their parents regarding disability issues and their access to services. The study also examines service provision for the South Asian parents and the perceptions of the service providers of South Asian disabled children and their parents.

The Social Model of Disability was used to identify and explain the treatment of the South Asian disabled children/young people and their parents by society and service providers. The participants' experiences were deconstructed and reconstructed to uncover the role of wider social structures in shaping their experiences. Semi-structured interviews were used to collect the views of South Asian disabled young people and their parents respectively. Telephone interviews were conducted with service providers.

The study revealed that the individual (and medical) model dominated the lives of the participants despite an increased awareness of the Social Model of Disability within society and service provision. The South Asian disabled children/young people and their parents experienced disabling environments within their own communities, the wider society and service provision. The parents' ability to advocate effectively for services and care for their disabled children was restricted due to a lack of information regarding their children's impairments, the services that were available and their children's future. A failure to raise their awareness about legislation that is pertinent to them and their disabled children, denied them the right to legislative processes to access their rights, and therefore, citizenship. Disability, Black and Minority Ethnic services tended to focus on disability or ethnicity, which meant that experiences arising from both were not being addressed.

CHAPTER 1 INTRODUCTION

This chapter introduces the study and is structured as follows:

(1.1) Conceptualising race and disability

(1.2) Background

(1.3) How this study differs from other studies

(1.4) Structure of the study.

1.1 Conceptualising race and disability

In this section I explain the main concepts of race and disability used in this study.

1.1.1 Race

The concept of race (or races), in which groups of people are considered biologically and naturally inferior due to physical appearances such as *"...skin colour, hair type, stature and facial appearances..."* (Fenton, 1999:5) is contentious (in sociology) and has been discredited (Carter, 2000; Fenton, 1999; Solomos, 2003; Harvey, 1990; Gunaratnam, 2003). However, notions of superiority and inferiority in the relationship between groups of people due to such markers continue to manifest themselves through race ideas and processes such as racism, which results in differential treatment and outcomes between different groups of people (Carter, 2000). According to Solomos:

> *Taking the concept of race first, notwithstanding the long history of debates on this term it has long been recognised that races do not exist in any scientifically meaningful sense. Yet it is clear that in many societies people continue to act as if race exists as a fixed objective category, and this belief is reflected in political discourses and at the level of popular ideas. Commonplace classifications of race have relied on a variety of variables – such as skin colour, country of origin, religion, nationality and language – to define groups of people (2003:10)*

Race ideas have historical specificity in time and space for their construction, production and reproduction. For example, colonialisation played a significant role in the construction and globalisation of the notion of superiority and inferiority in the relationship between different groups of people, based upon

physical appearances, religious and cultural practices, and psychological abilities (or perceived inability) (Fenton, 1999). During the 18th – 20th century, *"...Middle Eastern, Far Eastern, Malaysian, Indonesian, North, Central and South American, Caribbean, Pacific and African societies..."* were dominated by *"...European states in particular Portugal, Spain, Britain, Holland, France, Belgium, Germany and Italy"* (Fenton, 1999:70). These nations in their quest to increase individual and national wealth promoted negative ideas about the indigenous people in the lands that were supposedly discovered. For example, *"The Negro was held to be peculiarly sexual, musical, stupid, indolent, untrustworthy and violent"* (Walvin, 1982:60). The Christian church also supported the view that the people who were dominated were different, dangerous and incapable of managing themselves and required management and/or conditioning to be like their colonisers. In the construction of 'otherness', groups of people were compared to the assumed natural superiority of the colonisers who considered themselves as a superior race, which helped to justify colonisation. Eugenic theories of the 19th century also helped to promote an ideology of the natural order of the races based upon attributes such as skin colour and size of skull that has now been discredited (Fenton, 1999). Eugenic theories also extended to other groups of people, such as people with perceived impairments, who were considered to hamper the progression of a superior group and industrialisation. The culmination of this belief can be seen in the extermination of people with impairment, Jewish people and other minority groups in Germany during the 20th Century.

Race ideas have permeated through time and have been reproduced through racism – the processes of 'economic power, exploitation and exclusion' of groups of people resulting in their marginalisation (Gunaratnam, 2003). According to Solomos:

> *... racism is broadly defined in that it is used to cover ideologies and social processes that discriminate against others on the basis of their putatively different racial membership. .... In countries such as Britain racism is produced and reproduced through political discourse, the media, the education system, and other institutions (2003:11)*

Social policy in areas such as immigration illustrates how race ideas inform policy that could result in the racialization of the Black and South Asian communities in Britain. From 1945 greater numbers of people from the Commonwealth countries entered Britain to answer the call for labour to re-build the country after the Second World War (Carter, 2000; Solomos, 2003). The right to enter Britain to work by citizens from the New Commonwealth countries and Pakistan did not however extend to the right to access the same statutory services and welfare service as the indigenous population. There was also tension within the indigenous population about the new people entering Britain and coming to live within their local communities. They feared that the 'Empire was coming home' - people who were considered dangerous, unworthy and different were living in the country and it was mistakenly thought they had access to the employment market, statutory and welfare services. There was also fear that the cultures and beliefs of the immigrants from the New Commonwealth countries and Pakistan might prevent their assimilation into the British way of life. This supposed threat to the British way of life was seen as more of a 'problem', than the racism that was experienced by these communities in attempting to access well paid jobs and statutory and welfare services. The response of the British government to social tension was to curb immigration from New Commonwealth countries and Pakistan through restrictive immigration policies, such as the introduction of the 1962 Immigration Act and subsequent Acts. This legitimised the view that people from the New Commonwealth countries and Pakistan (African Caribbean and South Asian people) were a 'problem'. For example, immigration control did not seem to extend to people from Ireland (Solomos, 2003). Mac an Gahaill argues that the analysis of racism in British sociology has concentrated on the economic and social exclusion of Black and South Asian communities resulting in a 'silence' concerning the racism experienced by other immigrant groups such as Irish people (1999:20).

Mobilisation

The response to the economic and social difficulties, and social exclusion that were experienced by the immigrants from the New Commonwealth countries and Pakistan was of community support and political mobilisation. Community organisations were formed by some members of African Caribbean and South Asian communities respectively to support their communities. Activists within African-Caribbean and South Asian communities also came together under the political term black, in recognition of their common experience of racism due to their non-whiteness, although the construction of the term and their experiences of racism differed (Brah, 2000). However, the use of the term black has been criticised as being insufficient to describe the cultural aspects of South Asian communities, and not all South Asian people identified themselves with the term black. Hall argues that not all black people identified with *"that collective term"* (2000:151). In this study the term black is used to refer to African-Caribbean and South Asian people who have similar encounters of racism and therefore social exclusion in British society.

Responses by the government to address rising social tension in British society included the introduction of the Race Relations Act 1965, 1968 and 1976, which made racial discrimination illegal. However, a weakness in the Race Relations Act 1976 was that the existence of institutional racism in statutory functions was not acknowledged. However, the Stephen Lawrence Enquiry (CRE, 1999) identified the existence of institutional racism, which is defined as:

> *The collective failure of an organisation to provide appropriate and professional service to people because of their colour; culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people (CRE, 1999:2)*

The government responded to the Stephen Lawrence Enquiry (CRE, 1999) by introducing The Race Relations (Amendment) Act 2000, which imposes a duty on most public bodies to improve race equality through a race equality plan (CRE, 2000). According to the CRE:

> *In practice, this means that listed public authorities must take account of racial equality in the day-to-day work of policy-making, service delivery, employment practice and other functions (CRE, 2002b:1)*

Flynn (2002) argues that this should provide opportunities to encourage local authorities to promote their services to BME communities. It should also encourage systematic ethnic monitoring within services, which has generally been lacking (CIO, 1987; Mir et al, 2001; Flynn 2002). However, the CRE's recent evaluation has found that *"A significant number had not done anything to comply with the law..."* (2003e:1). This indicates the low priority that is accorded to attaining racial equality within some public bodies. The Chair of the CRE argues that services are admitting to institutional racism as a way of opting out of dealing with discrimination, because it is seen as nothing to do with them (CRE, 2003d). However, the recent European Union Race Directive – Directive no.2000/43/EC (Race Equality Unit, 2003), should help to strengthen existing race legislation in the UK (CRE, 2003b). It sets minimum standards regarding the equal treatment of people regardless of their racial or ethnic origin and is incorporated into the Race Relations Act 1976. The changes are reflected in The Race Relations Act 1976 (Amendment) Regulations 2003 (ibid).

Another contribution to reducing social tension between the indigenous population and immigrants from the New Commonwealth countries and Pakistan was the promotion of the idea of tolerance of different cultures in British society through the notion that Britain was a multi-cultural society.

According to Fenton:

> *...the term 'ethnic' or 'ethnic group' is used primarily in contexts of cultural difference, where cultural difference is associated above all with an actual or commonly perceived shared ancestry, with language markers, and national or regional origin* (Fenton, 1999:3/4)

However, the promotion of multi-culturalism through raising awareness of the cultures and religions of different groups of people through statutory services such as education, led to a criticism from an anti-racist perspective that embracing other cultures and religions did not address racism that was being experienced by African Caribbean and South Asian communities. The view that the cultures of African Caribbean and South Asian communities are 'problematic' and prevent their assimilation into the British way of life was also transmitted to their children – second generation immigrants born in Britain. The term ethnic/ethnicity is often used to refer to the cultural backgrounds of individuals and groups as social markers of difference. Perceived cultural differences (ethnic backgrounds) however, could be used to reinforce comparisons between groups of people, with the attendant danger of creating fixed boundaries of difference, similar to those created along race ideas. The recent debates regarding characteristics of Englishness and Britishness illustrate how these views can be deep rooted. As Brah argues:

> *The modalities of difference inscribed within the particularities of our personal and collective historical, cultural and political experience – our ethnicities – can interrogate and challenge the strangulating imagination of racism, but the task is a complex one, for ethnicities are liable to be appropriated by racism signifiers of permanent boundaries. Hence, the 'Englishness' of a particular class can come to represent itself via racism as 'Britishness' against those ethnicities that it subordinates – such as those of Irish, Scottish, Welsh, black British, or the ethnicities of the formerly colonised world. But, as I noted earlier, 'white'/European ethnicities are subordinated differently from non-white, non-European ethnicities (Brah, 2000:443/444).*

The cultures of African-Caribbean and South Asian communities are still considered to be a 'problem', and seen to be threatening the British way of life (Solomos, 2003).

In this study the term South Asian refers to people with ethnic/family origins from India, Pakistan, Bangladesh, Sri Lanka and Goa. The term black refers to African-Caribbean and South Asian people who have similar encounters with racism in British society (Brah, 2000). The term Minority Ethnic refers to people who experience processes of racialization due to their minority status in British society.

Summary

The concept of race is about ideas (refuted in sociology) emerging from biological/natural differences between people based on physical markers of difference such as skin colour, which suggest that this is fixed. Culture is about social markers such as ancestry and language (not fixed) but the cultures of other groups of people are seen as different to those of the indigenous people of Britain. When comparisons are made, it is the latter, which is assumed to be 'better'. The cultures of other groups are also seen as preventing their assimilation into the British way of life and also threatening this from within, as groups such as South Asian communities are viewed as unable to and/or unwilling to adapt to the British way of life. This reflects the ideology of new racism which does not refer to racial differences but which focuses on cultural differences and threats to the indigenous culture, thereby evoking a feeling of nationalism. There is a danger that cultural comparisons based on ethnicity (culture) between different groups of people and the indigenous culture may be viewed as equally fixed and unchanging as previous biological/natural theories of race, leading to similar notions of racial superiority.

1.1.2 Disability

The disability movement in Britain influenced the political agenda, which is illustrated by the introduction of the Disability Discrimination Act 1995 (DDA 1995). The DDA 1995 provides new rights for disabled people not to be treated unfairly (without justification) due to disability when accessing goods, services, facilities, buildings (housing/accommodation and so forth), employment and education (DRC, 2002). The DDA 1995 is aimed at reducing the social exclusion disabled people experience, for example by expecting service providers to change the way services are provided to enable access by disabled people. However, the DDA 1995 was (and is) considered weak by many people within the disability movement (Drake, 1999; Priestley, 1999a; Gooding, 2000; Swain et al, 2003). Some of reasons for this are:

- A medical definition of disability is used to define disability:

  > *a person has a disability for purposes of this Act if he has a physical or mental impairment which has substantial and long-term adverse effect on his ability to carry out normal day-to-day activities (Leicester Centre for Integrated Living, 1999:5).*

- Unfair treatment can be justified (for example by services).
- The onus for proving discrimination that is experienced is upon the individual.
- Disability Task Force was established to advise government policy regarding disability, which led to further campaigning by the disability movement for a Disability Rights Commission (DRC) similar to the Commission for Racial Equality and the Equality Opportunities Commission.

Oliver (1998) argues that by defining disability from a traditional, individual and medical perspective, impairment is viewed as the cause of the social exclusion that disabled people experience, rather than the way society is structured (the social barriers that they experience). Therefore the call by disabled people for inclusion in mainstream life and services by making changes to these is considered "*unrealistic and unnecessary*" (Oliver, 1998:90).

Oliver also argues that the policy of social inclusion for disabled people should be about attaining social rights rather than meeting individual need.

Despite its weaknesses the DDA 1995 makes discrimination against disabled people illegal and is a start to putting disability on the political agenda. In recent years there has also been a growth in policy initiatives regarding disabled people, for example:

- The Valuing People strategy (DoH, 2001) outlines ambitious plans to include disabled children and adults with learning difficulties in mainstream life. It aims to create seamless 'cradle to grave' services for disabled people, through various stages of life.
- Direct payments to disabled people who are 16 years of age and over to manage their care and therefore have greater control over their lives. However, an under use of direct payments, particularly by those with mental health difficulties and BME disabled people has been reported (Butt et al, 2000; Swain et al, 2003). This could be due to a lack of information and support to manage employment and financial matters, which can be a daunting task for those who are unfamiliar with these. Scrutiny of how direct payments are managed could be off-putting (Pearson, 2000).
- Carers are also given the right to an assessment (DoH, 2001). The National Carers Strategy is aimed at 'caring for carers' through greater access to information, better support services and improved finances, via the Carer's grant (ibid; Hatton et al, 2002).

The above reveals a growing political awareness of disabled people's social exclusion and the disability movement's success in influencing the political agenda through the framework of the Social Model of Disability. The table below identifies the key features of the social, individual, tragedy and rehabilitation models of disability, which I define next.

Table 1: Key features of the models of disability

Model	Key features
Social Model	Societal barriers prevent disabled people's participation in mainstream life and activities. Attaining civil rights for disabled people and their inclusion in mainstream life. Disabled people to have control over their lives. *Weakness:* Focus on disability discrimination and lack of acknowledgement of impairment, race, gender, age, and sexuality that compound some disabled people's experiences.
Individual and tragedy model	Disabled individuals considered a problem. Impairment considered a limitation, and disabled individuals seen as 'deficient', incapable and requiring care. *Weakness:* Powerlessness of disabled individuals. A lack of acknowledgement of social factors that limit disabled people's participation in mainstream life.
Medical model	Labelling of individuals through diagnosis. Access to services defined through a medical label. Treatment, cure and/or rehabilitation suggested for the individual to 'fit into' the status quo. Disabled people considered 'defective' and incapable of self-sufficiency. *Weakness:* focus on treatment and cure for disabled individuals to be non-disabled. Lack of acknowledgement of social resources and factors that impact upon disabled people's lives. Disabled people's lack of control over the decisions that affect their lives.
Rehabilitation model	Adaptation of disabled people to live as disabled people in a non-disabled world. Adaptation of disabled people through aids, equipment and learning the social conventions of non-disabled people to be like them and part of the status quo. *Weakness:* disabled people are not allowed to be individuals but expected to be like non-disabled people.

1.1.2.1 Social Model of Disability

The Social Model of Disability (Social Model) promotes the view that it is the way that society is structured (environment, economic, social and political structures), that prevents disabled people's participation in mainstream life, rather than impairment (Oliver, 1990, 1996a/b, 1997; Finkelstein, 1993a/b; Crow, 1996; Barnes and Mercer, 1997; Barnes et al, 1999). The Union of the Physically Impaired Against Segregation (UPIAS) provided a social interpretation about the social exclusion and discrimination that was experienced by people with impairments, due to social barriers rather than biologically determined barriers (such as the individual's impairment as preventing participation in mainstream life). According to UPIAS:

> *In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS, 1976:3/4)*

UPIAS assisted the disability movement in Britain to collectivise disabled people's experience of social exclusion for social change. The Social Model of Disability, provided a conceptual tool (Vernon, 1999; Swain et al, 2003) by which the interaction between society and disabled people could be identified and analysed (Williams, 2001). It showed that disabled people's access to services such as health, education, welfare, employment and leisure was not equal to non-disabled people because they experienced barriers to these and therefore were excluded (Oliver, 1990; Barnes, 1994; Barnes et al, 1999; Drake, 1999). Non-disabled people also had choice and control about the decisions that affected their lives, which disabled people were generally denied. Historically, in western society, disabled people have been considered inept and unworthy to make decisions and participate in social life because of impairment, which is based on notions of physical and mental perfection (Rieser, 1995; Winzer, 1997). Individuals with impairments were (and are) generally considered 'imperfect' and their abilities (biological, physical and psychological) to perform daily social tasks in their lives, including social and economic activity, assumed to be affected by impairment. Consequently, disabled people are generally considered incapable, and disability is considered a *"personal tragedy for individuals so 'afflicted'..."* (Oliver, 1993:50). Tragedy is strongly linked to the individual model because the disabled person is viewed as a victim and generally seen as dependent on other people for their care (Barnes et al, 1999; Priestley, 1999a), attitudes which are reinforced by the popular media. According to Hevey:

> *Whether in television, theatre, cinema, fine art or charity advertising, the tragedy principle uses impairment as a metaphor and a symbol for a socially unacceptable person and it is this tragedy principle, which is the bone-cage surrounding historical and current disability representation. It is this impairment-as-flaw that is 'negative' representation, and this form is intolerable (1993:118)*

Whilst in recent years, 'disability arts', has strived to reconstruct the image of disability (Hevey, 1993; Swain et al, 2003), the general solution from the individual and tragedy perspective is for individuals with impairments to be cured, corrected, rehabilitated and/or cared for (ibid, Priestley, 1999a; Brett, 2002). This process usually begins with medical intervention, in which the medical profession determines that the person is impaired and suggests ways in which they could be corrected to fit into 'normal' life. Thus the individual and tragedy model is strongly linked to the medical model (Connors and Stalker, 2003) as Barnes et al argue:

> *The recommended solution lies in curative and rehabilitative medical intervention, with an increasing involvement of allies health practitioners, psychologists and educationalists. To acquire impairment is to become the object of professional attention* (1999:21)

1.1.2.2 The medical model

The medical model is based upon clinical definitions, which labels the person as impaired (Oliver, 1990). The medical profession has the authority to conduct diagnosis based upon their medical 'expertise' and to prescribe treatment and/or rehabilitation (Oliver, 1990; Williams, 2001). Their role in the diagnosis of impairment (functional limitation) and the consequential treatment and/or care of disabled people expanded during industrialisation when a range of people, including disabled people, were viewed as economically unproductive and were segregated in asylums (Oswin, 1998; Oliver, 1990). The segregation of disabled people resulted in a growth of the 'disability industry', which included allied professions such as physiotherapists and occupational therapists, and carers (Barnes et al, 1999). The medical profession has retained the power to certify a person as 'disabled' and therefore allow them to qualify for specialist (disability) services and benefits (Altman, 2001). For example, to be entitled to some benefits, visually impaired people have to be certified as 'officially' blind or partially sighted, by the consultant ophthalmologist (French et al, 1997; Social Services Inspectorate, 1998). Visually impaired people, who are denied certification are subsequently denied access to services and benefit entitlement (Walker et al, 1992).

Thus the power of certification and therefore access to benefits and services can rest with (medical) consultants and subsequent welfare professionals who provide the services to which visually impaired people are entitled.

Oliver (1990) argues that focus upon a medical solution to impairment leads to the medical management of impairment, in which the adjustment of the individual is sought, through treatment and rehabilitation, rather than the adjustment of social barriers (Oliver and Barnes, 1998). This perpetuates the dominant ideology in society, that people with impairments are defective and require cure and/or care, and is illustrated by the association of impairment with deviance by the American sociologist Parsons (1951) (Oliver, 1996). According to Oliver (1996), Parsons suggests that disabled people take on the 'sick role', so that they can be excused from their social-economic duties, because of the general assumption in society of their inability to contribute usefully in these areas. Therefore an assumption is made that disabled people are unable to be self-sufficient and need looking after (Oliver, 1996), which is reinforced in society through the media and policy (Oliver, 1993; Hevey, 1993; Rieser, 1995; Priestley, 1999). Swain et al argue that:

> *Physical impairment represents a threat to established notions of discipline and normality because it serves to draw attention to uncontrollable nature – to limitations placed upon the ability of humans to shape and organize the world around them as they wish. Impairment signifies disorder, indiscipline, unreliability…and, as such, it is perceived as undesirable, something to be cured, overcome or hidden (2003:23)*

As a result there is an expectation in society that people with impairments should, through medical treatment and rehabilitation, fit into 'normal' life.

1.1.2.3 The rehabilitation model

Rehabilitation is linked to the medical model because it focuses upon correcting the individual through medical treatment and/or teaching them to be 'normal' through services such as education and social care.

Barnes et al argue that:

> *The formal emphasis was on skills development and helping people to take care of themselves. The goal was to identify ways to help them fit in or cope with 'normal' life and expectations so that they did not become a burden on the rest of society (Barnes et al, 1999:20)*

There is also a focus on improving the physical and functional abilities of disabled people that could include the image of the body, through corrective and cosmetic surgery to "*'normalize' the disabled body*" (Swain et al, 2003:103). In education also there is a concentration on the improvement of the health and physical abilities, and the social skills of disabled students rather than academic abilities (Barnes et al, 1999). Consequently disabled young people leave education with fewer transferable skills, which hampers their opportunities to access further education, and employment (Oliver, 1996b).

People with on-set impairment, such as people who are impaired as a result of an accident, war, and illness have a previous non-disabled state to rehabilitate to, but the people born with impairments do not have this opportunity (Finskelstein, 1993a/b). Consequently, people with impairments are generally not accepted as individuals, but expected to be 'normal' (like non-disabled people) and therefore someone or something that they are not.

The medical model is a sub-set of the individual model of disability because it considers disability to be an individual problem. The individual is considered to be defective and incapable of being self-sufficient without support, and is expected to adjust to fit into 'normal' life through medical treatment and/or rehabilitation (Finkelstein, 1993b; Priestley, 1999a; Swain et al, 2003). In general, the social barriers that people with impairment experience are not regarded. However, according to the Social Model it is social barriers that prevent the inclusion in social life of people with impairments and not necessarily their impairment, and therefore social barriers need addressing (and changing) rather than the individual (Oliver, 1990; Oliver and Barnes, 1998).

The Social Model is concerned with attaining social change through addressing the social barriers that prevent disabled people's participation in mainstream life. It is also concerned with enabling disabled people to engage in collective action to achieve social and political change so that they have equal access to civil rights and citizenship (Crow, 1996; Brett, 2002). This means that disabled people have choice and control over decisions that affect their lives as well as independence to exercise their rights. Consequently, making mainstream society inclusive to disabled people (as equal citizens to their non-disabled peers) through collectivising, rather than individualising, their experiences of social exclusion is fundamental to the Social Model.

1.1.2.4 Critique of the Social Model of Disability

Although the Social Model has been a major catalyst for placing disabled people's experiences of social exclusion and their fight for social justice on the political agenda, it has been criticised for focusing upon social barriers, and disregarding the limitation and/or pain that impairment can impose on some people's experience, and/or the necessity of medical intervention (Ahmad, 2000; French, 1993; Crow, 1996). For example, French argues that:

> *...some profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation* (1993:17)

As a visually impaired person, French (1993) argues that the difficulties she experienced, such as being unable to read non-verbal cues, are inherent to her impairment and therefore the removal of social barriers would not improve her situation. However, the Social Model does not disregard the role of impairment and medical intervention in the lives of people with perceived impairments, but focuses on social barriers with a view to offering an avenue to identifying the needs arising out of impairment and for these to be addressed, which includes being part of the decision-making process (having control over how the impairment is managed). According to Oliver (2004):

The social model of disability does not ignore questions and concerns relating to impairment and/or the importance of medical and therapeutic treatments. It acknowledges that in many cases, the suffering associated with disabled lifestyles is due primarily to the lack of medical and other services. It is similarly recognised that for many people coming to terms with the consequences of impairment in a society that devalues disabled people and disabled lifestyles is often a personal tragedy. But the real misfortune is that our society continues to discriminate, exclude and oppress people with impairments viewed and labelled as disabled (2004:22).

Oliver (2004) also argues that there is conceptual confusion in the argument about whether the Social Model acknowledges impairment, because impairment is about individual experience of impairment and the Social Model is about identifying the social treatment of people with impairment and collectivising these as a group of people who have common experiences of social exclusion. In focusing upon social barriers the Social Model de-pathologises the notion of individual responsibility for the impairment and therefore being excluded from mainstream life. Impairment is the functional limitation that is experienced by the individual as a result of which they might experience differential treatment in society. Morris (2000) contends that the Social Model separates impairment from disability, which helps to identify mechanisms in society that socially, exclude disabled people.

Shakespeare and Watson (2002) argue that the Social Model might be an outdated concept and suggest that it is time to start again, because of its failure to take into account disabled people's experience of impairment. They argue that the removal of social barriers is important and could *"co-exist"* with the relevant response to the prevention of impairment. They argue that all human beings in some way are impaired, as revealed by the Human Genome Project, and propose *"an embodied ontology"* that they feel reflects this.

According to Shakespeare and Watson:

> *We believe that the claim that everyone is impaired, not just 'disabled people', is a far-reaching and important insight into human experience, with major implications for medical and social intervention in the twenty-first century (2002:29)*

However, to claim that we are all in some way impaired does not necessarily reduce and/or eliminate the social barriers that prevent people with impairments accessing mainstream life and services. A more useful claim could be that all of us have the potential to experience disabling environments in the future due to illnesses, accidents and old age, which could have an impact upon our abilities. Therefore a more useful argument could be that an environment that is accessible to people with impairments could potentially benefit us all.

In this study, the term disability and disabled refers to the social exclusion that is experienced by children and people with perceived impairments. The term impairment refers to the functional limitation experienced by an individual with impairment.

Disability and ethnicity

The Social Model has also been criticised for the lack of recognition of factors such as ethnicity, gender, age and sexuality that could compound the discrimination that is experienced by people with impairments, who have more than one attribute that defines them as the 'other' (Priestley, 1995/1999a; Stuart, 1996; Vernon, 1996,1999; Shakespeare, 1997; Moore et al, 1999; Ahmad et al, 2000). Regarding disability and ethnicity, Stuart (1996), argues that black disabled people's experience of racism and disabilism, cannot be viewed as a 'double oppression', but as 'simultaneous' (Carby, 1992) similar to black women's arguments regarding their experience of sexism and racism.

However, Vernon argues:

> *...that this is too simplistic an analysis to capture the day-to-day experience of those who posses negatively labelled multiple identities (1999:385)*

According to Vernon (1999) disabled people live in a hierarchical society in which individuals could be part of the dominant and subdominant group, and could therefore have singular, multiple and simultaneous identities. For example, as a South Asian woman with a hidden impairment, I have a multiplicity of identities in which I have the potential to be the oppressor and oppressed. I could potentially experience sexism and racism but as a non-disabled adult I could potentially dominate children and young people, and disabled people. Thus BME and South Asian disabled people's identities need to be considered within a situational context (of where they are at the time) in which they might experience singular, multiple and simultaneous identities (Vernon, 1999). Vernon (1999) argues that a holistic application of the Social Model is required in which the factors such as ethnicity, gender, sexuality, age and class that could compound the experiences of disabled people are considered.

Appropriateness of the Social Model to South Asian disabled children/adults

Another criticism of the Social Model is of its appropriateness to South Asian communities, since according to Ahmad:

> *...some of the arguments about loss of control or independence, in relation to the social model of disability, may seem over-westernized to many, for whom interdependence, mutual support and reciprocity are the hallmarks of social and family relationships* (2000:2)

The concept of independence could be alien to some South Asian parents, who view the relationship with their children as interdependent and reciprocal (Ahmad, 2000; Atkin et al, 2000). Parents, particularly those with disabled children, have important roles as nurturers and carers as well as mediators (Read, 2000) between their children and services that intervene in their lives.

South Asian parents and families are also the main buffers against racial and disability discrimination that they and their children experience, both within their own communities and the wider society (Read, 2000; Ahmad, 2000). However, South Asian families and communities could also be sites of oppression, which could marginalise South Asian disabled people, their families and/or carers (CIO, 1987; Vernon, 1999; Ahmad, 2000; Katbamna et al, 2000). However, Swain et al argue that:

> *All human societies are characterized by interdependency, but some countries and cultures are more oriented to collectivism than individualism (2003:77)*

They argue that we are all dependent to some extent on other people for physical, emotional and social support. Therefore we are not completely independent, but are mutually interdependent (Oliver, 1993). Furthermore, interdependency exists between professionals and disabled people because those people who are involved in the 'disability industry' depend on disabled people for their employment (Swain et al, 2003). Swain et al (2003) contend that the narrow professional definition of independence such as enabling disabled people to achieve independence through rehabilitation to participate in social life has been re-defined by disabled people to mean taking control of their lives. A way in which disabled people have achieved this is through 'Direct Payments', which allow disabled people 16 years of age and over to purchase their own care, although it has generally been under used (ibid).

Oliver (1993) argues that disabled people's dependency is socially constructed and it is the ideology that disabled people are incapable because of impairment, which is transmitted through social policy (and the media) that compounds their dependency. Therefore disabled people's quest to attain independence and to take control of their lives is about rejecting the notion of enforced dependency, which defines them as powerless in their own lives and in the wider society.

This is recognised by some BME and South Asian disabled young people to whom independence means having a choice in their lives and being involved in decision-making processes, rather than living independently from their families (Bignall and Butt, 2000a/b; Hussain, 2002; Vernon, 2002). According to Bignall and Butt:

> *Exercising control over various aspects of life was a vital component of independence for many of these young black disabled people. They expressed their ideas of independence in terms of exercising rights and making choices. What mattered, it seemed, was having the opportunity to be involved in decision-making (2000b:6)*

Consequently, independence could have different meanings to different people, according to Swain et al:

> *...the meaning of independence and the ways in which it is manifested is determined by a wide range of cultural, historical, political, social and economic factors, which are volatile and vary both with and among cultures (2003:79)*

In this study, the Social Model is used to examine the experiences of the South Asian disabled children/young people, their parents and service providers. I also acknowledge the interdependent relationship that exists (Ahmad, 2000; Atkin et al, 2000) in some South Asian communities and also consider their respective 'norms', cultural, traditional and religious values (Ahmad, 2000). According to Barnes et al:

> *...disability is regarded as 'socially created' and the explanation of its changing character is located in the social and economical structure and culture of the society in which it is found* (1999:2)

'Having a say'

Oliver (2004) argues that:

> *...the traditional voice for disabled people had been the big charities that are still largely run and controlled by non-disabled people. Recent Government initiatives like the establishment of the Disability Rights Commission (DRC) have done little to change this situation, although the number of organisations controlled and run by disabled people has grown steadily at both local and national levels. This trend must be sustained as the voice of disabled people is crucial to delivering on the social model (2004:20)*

I would argue that in order for disabled people to deliver on the Social Model, they need access to make informed choices in their own lives and as citizens, which has historically been denied to disabled people. Aspects that led to the mobilisation of disabled people was that of the need to collectivise their common experiences of economic, social and political exclusion and the denial of their voices being sought and heard in the decision-making processes that affected their lives. The disability movement was influential in placing disabled people's exclusion from mainstream life on the political agenda and for their voices to be heard in decision-making processes. For example, the creation of organisations of disabled people by and for themselves, which resulted in the formation of the British Council of Organisations of Disabled People, later known as British Council of Disabled People because it allowed both organisational and individual membership (Campbell and Oliver, 1996). A criterion for membership of this umbrella organisation was that organisations should be working with disabled people. The British Council of Disabled People adopted the Social Model, which was instrumental in providing a framework for identifying the treatment of disabled people in society and collectivising disabled people's experiences for political mobilisation through the *"emergence of the disability movement"* (Oliver, 2004:22). Therefore, I would argue that the Social Model is closely linked to the collectivisation and mobilisation of disabled people and for this to occur disabled people require access and opportunities to make decisions about their lives and for these to be heard on a personal and wider societal level.

In this study, the South Asian disabled children/young people are provided with the opportunity to 'have a say', which is in recognition of the possible social barriers (due to age, racial and disability discrimination) that they might experience in representing their views. By seeking their voices and making this heard through the research, the South Asian disabled children/young people's experiences of their lives and treatment by society should assist with addressing the barriers that they experience. In my view, 'having a say' is linked to the Social Model because it helps with the conscientization of individuals of their immediate, wider social and political environment and therefore possible politicization. As Campbell and Oliver argue:

> *Most of the people we interviewed, or others we have met in the movement, joined because they gradually came to realise that the problems they faced were not theirs alone and that the only solution, in the end, was to organise with others facing similar difficulties. As well as a desire to improve the conditions of their own lives, there was often a desire to improve those of other disabled people as well (1996:56)*

Table 2: Summary of definitions of the terms used in this study.

Race	A socially constructed concept discredited in sociology, in which social markers such as physical appearance (i.e. skin colour) are used to differentiate between different groups of people based on a notion of biological and natural superiority and inferiority.
Racism	The processes through which race ideas are promoted resulting in the marginalisation of racialized groups of people resulting in different outcomes.
Ethnicity/Ethnic group	Social markers identifying difference between groups of people based on culture, ancestry, religion and language.
Black	African-Caribbean and South Asian people who have similar encounters with racism in British society.
Minority Ethnic	Minority Ethnic refers to people who experience processes of racialization due to their minority status in British society.
South Asian	People with ethnic/family origins from India, Pakistan, Bangladesh, Sri Lanka and Goa.
Disability /disabled	Disability and disabled people (including children and young people) is used to acknowledge the social exclusion that they experience because of social barriers.
Impairment	The term impairment refers to functional limitation experienced by an individual with impairment.
Social Model	A conceptual framework, which helps to explain the treatment of disabled people in society and to identify the social barriers that exclude disabled people from mainstream life. Therefore the social barriers that are experienced by disabled people need changing rather than the disabled person.
Medical Model	Sub-set of the individual model, which promotes a notion of disability that views disabled people as individuals who require correction and/or care through medical treatment and/or rehabilitation, to fit into 'normal life'. Disability is seen as undesirable and a tragedy because it is viewed as a 'deficiency' and therefore the individual's ability to achieve self-sufficiency is doubted. The medical model is strongly linked to the individual, tragedy and rehabilitation models, in which the common view is that the disabled individual needs changing.

1.2 Background

The investigation of the experiences of South Asian disabled children/young people and their parents was influenced by my employment at the Asian Families Project at the Royal National Institute for the Blind (RNIB). I found a general lack of research regarding their experiences (Johnson and Scase, 2000). Yet empirical evidence was considered essential for planning services and anecdotal evidence was generally considered insufficient for planning services that met the needs of South Asian visually impaired children and their families. Although there is some information, (ABA, 1996; Ahmad et al, 2000, Ahmad et al, 2002; Ahmed, et al, 1997; Priestley, 1995, Shah, 1995) regarding South Asian visually impaired people, which highlights their experience of a lack of information and appropriate services, this is localised and small-scale and generally concentrates on adults. Consequently, there is little information that is grounded in the views of South Asian visually impaired children/young people and their parents. The experiences of parents with disabled children regarding their access to services are important because of their role in supporting their disabled children to achieve their potential in life (Chamba and Ahmad, 2000). A lack of access to information and services could restrict their ability to support their disabled children and, therefore, their children's capacity to achieve their potential. For example, I found that the South Asian parents of visually impaired children lacked information regarding their children's impairment. They also lacked access to services or experienced a delay in services that could assist them to stimulate their children's development at home. Consequently the ability to achieve their potential is hampered (Pogrund et al, 1992).

As a South Asian woman with a hidden impairment (congenital cataract), I have a personal interest in the issues regarding disability and ethnicity, in particular the experiences of South Asian visually impaired children/people and their families. My impairment has not affected my participation in mainstream activities and life (although it may do so in the future), and therefore I do not generally define myself as a disabled person.

The only indication that I have a 'defect' with my eyesight is the use of spectacles, due to which I have experienced some discrimination. However this was, and is, limited compared to the discrimination that people with obvious impairments might experience in society (French, 1994). Therefore I have an affinity with the experiences of disabled people and share one or more of the following with the participants in this study, ethnicity, language (English as a second language after Gujarati), immigrant status, gender, age and professional status. As a professional with a background in youth and community development work, and social welfare and care, I have a vested interest in empirical knowledge about the experiences of the South Asian disabled children and their parents contributing to an understanding of their experiences and helping to improve policy and practice. This should also enable social change in the lives of the South Asian disabled children/young people and their parents.

I am also aware, through my employment at the RNIB, and the literature search and review conducted for this study, about the growing interest and knowledge regarding the experiences of BME and South Asian parents of disabled children (Katbamna et al, 1998; Chamba et al, 1999; Ahmad, 2000; Mir et al, 2001; Flynn, 2002; Flynn and Patel, 2002; Hatton et al, 2002). Existing research highlights the disadvantaged position and barriers to service provision that are experienced by BME and South Asian disabled people and their carers (ibid). In recent years, there has also been some research regarding the views of BME and South Asian disabled young people (Bignall and Butt, 2000b; Atkin and Ahmad, 2000; Steele and Sergison, 2001; Patel, 2002; Hussain et al, 2002; Skill, 2003b). However, few studies have specifically included the views of BME and South Asian visually impaired children/young people. Consequently, this study includes the views of South Asian visually impaired children/young people. It also includes the views of their parents and service providers, which allows the phenomena (disability and racism) to be considered from different perspectives and therefore triangulated (Burgess, 1984; Seale, 1999; Siraj-Blatchford and Siraj-Blatchford, 2001b).

The PhD bursary awarded by De Montfort University enabled me to conduct a qualitative study, using methods such as the interview, to gather empirical data regarding the experiences of South Asian disabled children/young people, their parents and service providers. The specific aims and objectives of the study are:

Aims:

- To explore the experiences of South Asian parents of disabled children, including their access to services provided by statutory and voluntary organisations.
- To explore the experiences of South Asian disabled children and young people.
- To explore service provision for South Asian parents of disabled children and young people and how service providers perceive South Asian disabled children and their parents.

Objectives:

- To develop an understanding of the impact of having a disabled child upon Asian parents and the meaning South Asian parents attach to disability.
- To develop an understanding of how South Asian disabled children and young people view themselves, their aspirations and how they feel they are perceived in society.
- To develop an understanding of service providers' perceptions of how South Asian parents view disability.
- To improve service provision for South Asian disabled children/young people and their parents.

1.3 How this study differs from other studies?

This study differs from existing research in the following ways:

- The experiences of South Asian disabled children/young people, their parents and the service providers are sought in their own words, and therefore are grounded in their social reality.
- It uses Critical Social Research (CSR) (Harvey, 1990) to examine 'taken for granted' assumptions regarding the South Asian disabled children/young people's, their parents' and service providers' experiences.
- It uses the framework of the Social Model of Disability (Oliver, 1990,1997) to investigate the experiences of the South Asian disabled children/young people, their parents and service providers. The models of interaction between the three groups of participants are also examined.
- It examines whether the Social Model is applicable to identify the treatment of South Asian disabled children/young people and their parents and/or whether another model is required for this group.
- It analyses data using adaptive theory (Layder, 1993,1998) to maximise theory generation.
- It contributes to existing understanding about the experiences of South Asian disabled children/young people, their parents and service providers, which should inform policy and practice.

1.4 Structure of the study

The rest of this study is structured in the following chapters:

Chapter two – presents a critical review of the relevant literature regarding researching children, BME and South Asian disabled children and young people, and BME and South Asian carers of disabled children and adults.

Chapter three – discusses the methodology, which includes Critical Social Research (CSR) (Harvey, 1990), Social Model (Oliver, 1990, 1996a/b, 1997) and adaptive theory (Layder, 1993, 1998). This chapter includes a presentation of the design of the study, the methods that were used to conduct the study and a critique of these.

Chapters four to six – present and analyse the findings from the interviews with the South Asian parents, South Asian disabled young people and service providers, respectively.

Chapter seven – outlines the original contribution to knowledge that is made by this study, sets out recommendations and proposals for future work, before concluding with a review of how this study has met the University's requirement for a PhD stated in the Research Degree Regulations of the University (De Montfort University, 2000:3).

CHAPTER 2 LITERATURE REVIEW

In this chapter, I critically review relevant literature as follows:

(2.1) Researching children

(2.2) BME and South Asian disabled children and young people

(2.3) BME and South Asian carers of disabled children and adults

2.1 Researching children

In recent years, there has been an increased awareness both politically and socially regarding children's ability and their right to have a say in matters such as service provision and environmental issues (Adams and Ingam, 1998; Thomas and O'Kane, 2000; National Children's Bureau, 2002). The Children Act 1989 paved the way for children's views to be heard, in care, regarding the decisions that were made in their interest (Morris, 2001). This is the response of the UK government's ratification (in 1991) of the United Nations Convention on the Rights of the Child 1989 (UNCRC). The UNCRC gives children the right to express their views freely in all areas that affect them (Article 12) and the right to freedom of expression of their views as well as to receive information and to give information (Article 13) (Willow, 2002). The rights of disabled children to full participation and social inclusion are specifically mentioned in Article 13, although all the rights are accessible to them (ibid).

The 'new sociology of childhood' considers that the socialisation of children is an important area in shaping their lives, but that children should be (active) actors in the socialisation process and therefore in the construction (re-construction) of their childhood (James and Prout, 1997; James et al, 1998). This contrasts to the previous views of childhood and child development in which children were considered passive recipients in developmental strategies and socialisation processes which were aimed at preparing them for adulthood and their contribution as responsible adults to the economy and family life (ibid).

Listening to children in order to shape services and environments that meet their needs (Adams and Ingam, 1998; Morris, 2001; Willow, 2002) contrasts dramatically with the historical exclusion of children from decision-making processes and the right to participate equally with adults in society, because they were viewed as biologically (age), physically, psychologically and economically inferior (Beresford, 1997; James and Prout, 1997; Moore et al, 1998; Thomas and O'Kane, 2000). As a consequence there has been over reliance upon the views of adults regarding children's lives and a general lack of information about children's own views about their lives (particularly disabled and BME children) (Morris, 2001; Ali et al, 2001; Flynn, 2002). However, in the context of the 'new sociology of childhood' and also children's rights, children are regarded as citizens who are able to offer views that are equally valid to those of adults, and obtaining children's views is considered essential to shape services that meet their needs.

On a national policy level, the Department for Education and Skills (DfES) has produced the 'Listening to Learn' action plan to involve children/young people in policy-making processes (DfES, 2003). However, Morris (1998d) argues that disabled children/young people's views are often excluded in services. Morris's study (1998d) regarding the implementation of the Children Act 1989, as it applies to disabled children, found that there was lack of commitment and trained staff to seek the views of disabled children with communication difficulties. According to Morris:

> *Typically, the section of the form headed 'Child's view' was left blank or the social worker made comments such as, 'She is unable to verbally communicate and therefore her view is not available'; 'It is not possible to know what his views are owing to his level of disability' (1998d:2)*

Shakespeare and Watson argue that researching disabled children from the perspective of the Social Model should be based upon *"equality, inclusion and autonomy"* (1998:24).

Moore et al (1998) contend that the ethical consideration (informed consent, confidentiality, avoidance of risk to harm) and use of appropriate methods recommended for childhood research (Alderson and Goodey, 1996; Ireland and Holloway, 1996; Mahon et al, 1996; Beresford, 1997; Thomas and O'Kane, 2000; Connors and Stalker, 2003) applies to disabled children also. However, they argue that associating the children with disability pathologises them as different at the start of the research, yet such an association is often required to conduct the research, thus presenting a quandary for the researcher. They suggest that *"In writing up, researchers can always attempt to resist the most crude ramifications of this problem through judicious presentation of arguments..."* (Moore et al, 1998:73). Researchers could also include the participants in the design of the research (Morris, 1998c; Ward, 1999). Morris (1998c) and Atkinson and Williams (1990) recommend the use of disabled children's preferred methods of communication, (where they have cognitive and communication difficulties) and facilitators who are familiar to them.

In recent years there has been a growth of research that includes disabled children/young people's personal accounts about various aspects of their lives (such as: Cavet, 1998b; Morris 1998a/b/c; Stalker and Robinson, 1998; Middleton, 1999; Watson et al, 1999; Stalker and Robinson, 2003). On a national policy level, disabled children/young people are being included in policy and research initiatives such as Objective 8 of the Quality Protects Initiative for transforming services for children (Morris, 2001; Hatton, 2002; Connors and Stalker, 2003). The recent Audit Commission report (2003) 'Services for Disabled Children' involved disabled children/young people and found that there was:

- A *"lottery of provision"* – services were provided according to where the disabled children and/or their families lived.
- Service provision was *"often too little and too late"* to have a positive impact upon the disabled child and their family.
- Families had to go through a *"maze of services"* to obtain relevant information and jump through *"hoops"* to get support.

They also had to repeat their stories numerous times mainly because services did not work jointly to meet their own priorities (Audit Commission, 2003a).

- Disabled young people wanted the same opportunities that their non-disabled peers had to participate in mainstream life and leisure activities. They also wanted to be accepted, feel safe, be valued and listened to (Audit Commission, 2003b).

Watson et al's (1999) study 'Life as a disabled child' found that disabled children/young people experienced greater levels of *"surveillance by adults"* than non-disabled children, which resulted in a lack of privacy and reduced their opportunities to socialise with a wider group of young people within education settings and outside. Disabled children/young people's participation in mainstream activities was also limited by negative social attitudes towards disabled people and inaccessible environments, which for BME disabled children/young people, could be compounded by racism. Watson et al (1999) found that BME parents were hesitant to send their children to a setting in an area where racial abuse was rife. They also found that disabled children/young people were defined as disabled by the adults in their lives, which took prominence over other kinds of differences that might exist. However, to the disabled children/young people, disability was not a fixed concept and they identified with disability according to the situation in which they found themselves. The disabled children/young people retaliated to the definitions of disability imposed upon them by adults. Therefore they were not passive recipients of the treatment that they received from adults and their peers.

Connors and Stalker (2003) used the social-relational model of disability (developed by Thomas, 1999a), which considers the psycho-emotional well being of disabled people to examine the 'Views and experiences of disabled children and their siblings'. The experiences of the disabled children are similar to studies such as Cavet, (1998), Middleton (1999) and Morris (1998a/b/c) regarding social exclusion and bullying.

However, Connors and Stalker (2003) found that the disabled children described their experiences from a medical perspective, although they did not relate this to feelings of tragedy. The disabled children managed their experiences of being disabled and most felt that they would be employed in the future, although some felt that disability could deny them access to certain professions. The disabled children's views about professionals (such as in health services) were both positive and negative, although most thought of education professionals in a more positive light. Connors and Stalker's (2003) study includes the views of siblings. They found that to some of the siblings their disabled sister or brother was an integral part of their lives and they were not seen as different. However, some feelings of irritation and bitterness were expressed, particularly regarding the focus of the parents on the disabled sibling and societal attitudes. The siblings experienced being bullied because of having a disabled brother or sister and felt inhibited in reporting the bullying that they experienced.

2.2 BME and South Asian disabled children and young people

In recent years, research regarding BME and South Asian disabled children/young people that is grounded in their personal accounts has also increased. Studies regarding BME and South Asian disabled young people (such as: Bignall and Butt, 2000a/b; Hussain et al, 2002; Skill, 2003b) reveal that they, like their indigenous disabled peers, experience social isolation due to the over-protectiveness of their parents and disabling environments (inaccessible environments and negative social attitudes). They also experience lower expectations from teachers and adults regarding their ability to achieve their future potential, resulting in lack of support to enable them to achieve their aspirations. However, Bignall and Butt (2000a/b), Hussain et al (2002) and Skill (2003b) found that BME and South Asian disabled young people's experiences are compounded by racism.

For example, they reported that education was generally a negative experience, which did not prepare them for life after school because of the low expectation of teachers arising from factors such as racism and a lack of awareness about cultural and disability issues. Some of these participants felt that their education was hampered by a concentration on their physical abilities rather than academic abilities. However, those BME and South Asian disabled young people who were able to attend further education and employment of their choice found this rewarding (Skill, 2003b).

BME and South Asian disabled young people also experienced negative attitudes regarding disability in their own communities, which hampered their inclusion in religious and community activities (Ahmad et al, 2002). The BME and South Asian disabled children/young people experienced isolation within their own communities and the wider society, and had few opportunities to socialise with a wider group of disabled and non-disabled peers. Bignall et al (2002) found that peer support groups for BME disabled young people offered them a rare opportunity to explore issues relating to racism, religion and discrimination with their peers who had similar experiences. It also offered them a safer place in which they were unlikely to experience the racism that they encountered in disability centres and groups. For this reason BME disabled young people preferred BME peer support groups. Bethell and Harrison's (2003) study regarding a disabled young people's peer mentoring and support project found that supporting disabled young people to meet together and work out solutions to the common difficulties they experience could reduce barriers to independence. One-to-one support offered by their peers was found to be valuable, as was training in the Social Model of Disability.

Independence was an important aspect in most of BME and South Asian disabled young people's lives, which was generally defined as having a choice and being able to make decisions in their lives (Bignall and Butt, 2000a/b; Hussain et al, 2002; Vernon 2002).

For example, Bignall and Butt's (2000a/b) study regarding young black disabled people's views about independent living found that they defined independence as having choices and *"control in their lives"*, although this was sometimes determined by their families. Some BME disabled young people did not associate independent living as living apart from their families but being involved in decision-making processes about various aspects of their lives. Some of the parents in Bignall and Butt's (2000a/b) study gave their disabled children errands to encourage their independence, which improved their self-esteem. Bignall and Butt (2000a/b) also found that many of the BME disabled young people in their study did not want to be different to their non-disabled peers.

Atkin and Ahmad (2000) contend that children with chronic illnesses such as Sickle Cell Disorders (SCD) negotiate and take greater responsibility to manage their medication and pain, as they grow older. Medication and pain can also interfere with their identity as young people because it makes them feel different from their peers, which could result in non-compliance with medical regimes to avoid feeling this way. However, they also experience feelings of guilt particularly when non-compliance results in crisis. Atkin and Ahmad (2000) also found that the response of the medical professionals within hospitals is often based on ignorance regarding SCD and racist myths regarding Black people's thresholds of pain and dependency upon drugs. They also argue that SCD is considered an illness that affects mainly the Black population and therefore is under resourced in comparison with illnesses that affect the majority population.

Few studies mention BME and South Asian disabled young people's views about marriage. In general, studies regarding their experiences have failed to discuss issues relating to child-protection, and sexual and marital relationships, resulting in a lack of knowledge in these areas. However, the common message emanating from studies regarding BME and South Asian disabled children/young people is that they experience both disability and racism in their lives.

Yet, both the disability and the anti-racist movements have failed to acknowledge BME and South Asian disabled people's experiences of social exclusion due to disability and racism (Stuart, 1996; Vernon, 1996, 1997, 1999). Hill argues that:

> *...it is attitudes of able-bodied people from within their own ethnic communities, from the wider community and even from within the predominantly white disabled community, which restricts and dis-enables them* (1992:4)

However, whilst disabled people have collectivised and formed organisations that are run by and for disabled people (such as coalitions for disabled people and Centres for Integrated Living) and have created umbrella groups such as the British Council for Disabled People (Campbell and Oliver, 1996; Oliver, 1990; French, 1994; Barnes et al, 1999; Drake, 1999; Preistley, 1999a; Swain et al, 2003), Black disabled people have also formed self-help groups such as the Association of Blind Asians in Coventry, Leeds and London (Patel, 1996; Priestley, 1995; Shah and Priestley, 2001), and The Asian People's Disability Alliance (French, 1994; Drake, 1999), in response to their marginalisation from statutory and voluntary services. These groups were at the forefront of providing support and advice to disabled members in their communities, which is culturally competent (Shah and Priestley, 2001). More recently, the Joseph Rowntree Foundation has given funding to start a national forum to explore the needs of BME disabled people (Mark, 2003). This should provide a valuable opportunity to engage a wider range of people in a dialogue to address issues affecting BME and South Asian disabled people in the UK, both as disabled and black people who experience singular, multiple and simultaneous identities (Vernon, 1999).

2.3 BME and South Asian carers of disabled children and adults

There is also a growing knowledge regarding the experiences of BME and South Asian carers' (caring for a disabled person). The literature (such as: Shah, 1995; Katbamna et al, 1998; Chamba et al, 1999, Ahmad et al, 2000; Steele and Sergison, 2001; Flynn 2002; Hatton et al 1998, 2002) highlights BME and South Asian carers' experience of social disadvantage and exclusion, which is similar to the experience of indigenous carers (Beresford, 1994; Read, 2000). However, BME and South Asian carers' (and BME and South Asian disabled people) also experience individual and institutional racism, which affects their access to services and consequently their ability to care for a disabled member within their family. Barriers that inhibit BME and South Asian carer's (and disabled people's) access to services include:

- A lack of commitment to disabled people particularly to BME and South Asian disabled people in both government and municipal agencies
- Individual and institutional racism
- A separation of disability and ethnicity resulting in BME disabled people and their carers' exclusion from disability services and within their own communities
- Language barriers – those who can speak English are better informed about services and have greater access to them than those who cannot
- Lack of information
- Lack of culturally appropriate services
- A myth that BME and South Asian disabled people and/or members of their communities are supported within their communities (Shah, 1995; Patel, 1996; Katbamna et al, 1998; Chamba et al, 1999, Ahmad et al, 2000; Steele and Sergison, 2001; Flynn 2002; Hatton et al 1998, 2002).

Whilst some changes within service provision seem to have occurred such as meeting the dietary and linguistic needs of South Asian communities (Patel, 1993; Katbamna et al, 1998; Audit Commission, 2003), barriers seemed to have persisted.

For example, studies have continued to find that the linguistic needs of South Asian communities have not been fully met by services (Chamba et al, 1999; Steele and Sergison, 2001; Flynn, 2002; Flynn and Patel, 2002; Hatton, 2002). This suggests that prejudices regarding disability and racism are deeply rooted, which require political commitment for structural change (Ahmad, 1993; Patel, 1993).

According to the Commission for Racial Equality (CRE) *"'Non-white' ethnic minorities make up 7.1% of the British population..."* (CRE, 2003a:1). This means that BME communities are likely to both contribute to the economy and draw upon welfare and benefit services. Consequently, it could be increasingly difficult for service providers to justify a failure to meet their specific needs (such as language, diet). Furthermore, Hatton et al (2002) suggest that the prevalence rate of severe learning disability amongst South Asian communities may be three times greater than other BME groups in the UK. This means that there could be a greater demand for specialist services from South Asian communities in the future (Steele and Sergison, 2001). Yet studies reveal that there is a general lack of ethnic monitoring within services, which prevents service planning that considers the needs of BME/South Asian disabled children, adults and their families (CIO, 1987; Mir et al, 2001; Flynn, 2002; Flynn and Patel, 2002).

Luthra (1997) found that the social position of some South Asian communities has flourished, despite their concentration in low paid and insecure jobs and the difficulties they experienced in accessing welfare services and benefits, since their arrival in the UK during the 1940s (Williams, 1989). Luthra (1997) also argues that there are increasing numbers of the South Asian middle-class that are in business and homeowners. However, not all members of the South Asian communities have seen their economic situation improve, since according to Modood (1998) the average earnings of ethnic minority women were less than ethnic minority men, whose earnings were less than white men.

Ali et al (2001) argue that despite the heterogeneity within South Asian communities, they are often described as *"Asian"*, which does not take into account the differences that exist. For example, the Muslim community experiences greater marginalisation than other South Asian groups in the UK, as a result of the Rushdie affair (Luthra 1997; Mirza et al 1997; Modood 1998), and more recently, *"the attack on the World Trade Centre on September 11th 2001"* in the USA (Hussain and Bagguley, 2003: 9). Pakistani and Bangladeshi groups also experience greater rates of under-employment than other ethnic minority groups (CRE, 2003a).

Chamba et al's (1999) survey based on BME users of the Family Fund reveal that whilst BME disabled people and their carers experience greater financial hardship than their white counterparts, Pakistani and Bangladeshi families are the most disadvantaged. Greater levels of under-employment amongst the mothers, which reduced the overall family income, exacerbated the hardship that was experienced by BME families caring for disabled children and adults. BME families also received fewer disability benefits (and lower rates) than their white counterparts. BME families were also less well-supported by their extended families than their white counterparts, which confirms the findings of most studies that refute the assumption that BME and South Asian communities 'look after their own' (CIO, 1987, Shah, 1995; Qureshi et al, 2000). The lack of informal and formal support means that BME families experience greater isolation and less relief from caring for their disabled children than their white counterparts. Chamba et al (1999) also found that BME families' access to information regarding their children's condition, services and benefits depended upon their command of the English language. This is because information and services were mainly provided in English, which meant that those people who were not well versed in using English were at a disadvantage because:

> *Professionals failed to provide an equal service to speakers of languages other than English. Little knowledge of English, poor interpreting support and limited availability of translated materials make access to appropriate information difficult (Chamba et al, 1999:3)*

Chamba et al (1999) and Chamba and Ahmad (2000) report that BME families prefer information from direct sources such as professionals and written information, with telephone help lines in English and other languages being least popular. Steele and Sergison (2001) found that some of the Ethnic Minority families in their study welcomed information in their own languages, but few expressed a need for audio/video tapes as a way of addressing literacy in their own languages. The majority of the BME families in Chamba et al's study (1999) also lived in unsuitable housing and nearly half of the respondents reported housing problems, which included a lack of space, which restricted movement. This reflects the general situation regarding BME people's access to housing, according to the CRE:

> *Some ethnic minority groups are more likely to live in poor housing. 40% of Bangladeshi and Pakistani households live in overcrowded housing, reflecting a lack of larger housing and lower incomes. Rates of overcrowding for the Irish are twice those of the population as a whole (CRE: 2003a:4)*

Chamba et al's study (1999) reveals that the BME families caring for disabled children have greater needs, which however, are not fully met by services because they do not fully understand BME people's socio-economic position in Britain. For example, BME people experience greater levels of under-employment, lower paid employment, poorer access to welfare services and benefits, which contribute to poorer health (Dyson and Smaje, 2001). Chamba and Ahmad (2000) argue that since BME communities' access to welfare services and benefits is not equal to that of the majority population, this results in a lack of access to full citizenship.

Mir et al's (2001) review regarding 'Learning Disability and Ethnicity' found a general lack of BME advocates, resulting in a gap in the available services to enable BME disabled people to access their rights to services and therefore citizenship.

Mir et al (2001) also argue that there is a lack of BME workers within disability services, which has an impact upon the image of the services and their use. Mir et al (2001) and Flynn and Patel (2002) argue that the advantage of having BME workers is that it would:

- Reflect the make up of the local population and improve the image of the service as inclusive to BME users.
- Increase use of services because it could reduce BME users' apprehension of experiencing possible misunderstanding of their needs and/or racism.
- Influence agencies to be culturally competent (and therefore services to be culturally appropriate), which has been a factor that inhibits the use of services, such as short-break services, by BME communities (Chamba et al, 1999; Mir et al, 2001; Flynn, 2002; Flynn and Patel, 2002; Hatton et al, 2002).

Studies (Mir et al, 2001; Flynn and Patel, 2002; Shah and Priestley, 2001) have found that BME organisations are culturally competent, possibly because these are predominantly staffed and run by BME people who might have implicit understanding of racism and the needs of BME communities. However services staffed by BME people are often short-term and temporary, which restricts long-term development work occurring within these communities (ibid).

In Hatton et al's study (2002) regarding South Asian families with severely disabled children, whilst the majority of the families were two-parent, there was also a small number who were lone-parent families, who experienced lower levels of income. This is significant because there is a lack of research and therefore information regarding the experiences of BME and South Asian lone-parent families with disabled children, and/or indeed the disabled children's experiences of living in lone-parent families. A crucial finding from Hatton et al's (2002) study is that the South Asian parents caring for severely disabled children experienced physical and mental health difficulties (including depression), some of which were related to their anxiety about their children and having to fight for services.

These were also exacerbated by some of the parents' long-term illnesses and/or disability and by unmet need. Hatton et al suggest that:

> *Informal supports, along with formal service supports and an active family social life, also help to reduce parental depression. Parental distress and anxiety are more likely to be relieved if more of the family's needs are being met, the child is less of a problem to supervise, and the parent has fewer physical health problems (2002:116)*

BME disabled children's, adults' and their carers' access to services could be inhibited by service providers' perceptions about them. For example, Shah (1995) found that social workers had the following perceptions of South Asian parents with disabled children:

- They reject their child when diagnosed.
- They are stigmatised by their family and community.
- They view impairment as a punishment from God.
- Asian men are dominant, thus communication should be conducted through them.
- The extended family assists with caring.

This suggests that some professionals perceive other cultures as a 'problem', which could result in blaming South Asian users for the difficulties that they might experience in accessing services (Atkin, 1991; Ahmad et al, 1998). Atkin argues that:

> *Focusing attention on Black culture becomes classified according to the white norm and one of the consequences of this is the creation of a black pathology (1991:42)*

This means that Black people's beliefs, values and life styles are considered inferior and blamed for the hardship they experience in the UK. For example, health problems, disability and chronic illnesses experienced by South Asian communities are attributed to their life style and diet, which are considered inadequate for living in British society (Ahmad and Atkin, 1993; Ahmad et al, 2000).

These explanations predominate rather than those based on South Asian people's lower socio-economic position in the UK, inappropriate service provision and their experience of individual and institutional racism (Luthra, 1997). Ahmad (1993, 2000), illustrates the following ways in which racism (institutional) in services such as health is perpetuated:

- The assumptions of health professionals that it is the lifestyle of South Asian people that contributes to illnesses such as Rickets and their expectation that South Asian communities should assimilate into the lifestyle of the host culture, rather than considering ways in which Vitamin D could be introduced in their diet such as through flour, fortified with Vitamin D, used for chappatis. The concentration of health (and education) professionals upon consanguinity as a factor that contributes to a population of disabled children, and their expectation that these communities should change their marital practices to those of the host culture.

- The lack of appropriate research and services to BME people with sickle cell disease/thalassaemia, which is considered to affect BME groups, therefore not meriting resources that are allotted to illnesses that affect the majority population.

However, the recent introduction of the Race Relations (Amendment) Act 2000 should assist with attaining racial equality in public services. Some good practice within disability services has also been identified, by the recent Audit Commission report (2003a) 'Services for disabled children'. The report also states that more needs to be done and argues that existing policy initiatives regarding children/young people should provide levers for change.

Summary

The literature review revealed that there is an increasing knowledge regarding disabled children, BME and South Asian disabled children/young people and their families. The common theme that emanated is that disabled children and their families are socially excluded from mainstream life, due to social barriers such as negative societal attitudes and inaccessible services. However, the experiences of BME and South Asian disabled children/young people and their families are compounded by racism, which is illustrated by the difficulties that they experience with accessing services. Whilst the majority of the BME and South Asian experience disadvantage within their own communities and the wider society, Bangladeshi and Pakistani communities are more disadvantaged than other groups. In the next chapter I discuss the methodology that was adopted to conduct the present study.

CHAPTER 3 RESEARCH METHODOLOGY

In this chapter the theoretical framework, research methods and tools that were adopted for this study are presented in the following main sections:

(3.1) Theoretical and analytical framework: includes the principles of critical social research (CSR) and Social Model of Disability (Social Model). Aspects that are considered include the political commitment of the researcher required to explore 'taken for granted' assumptions about social structures and the participants' experiences, and to enable social change in the social situation of the participants. The principles of emancipatory research are considered and the main tenets of adaptive theory such as: multi-methods/strategy approach, analysis and theorizing, use of prior, existing and general theory, and the connection with wider social structures are also presented. The processes of going back and forth in the data to aid theory generation, data coding/analysis, and reliability and validity are set out.

(3.2) Research methods and tools: includes an overview of how the study was conducted, an account of a purposefully selected sample and discussion about how the participants were identified and accessed. The rationale for using qualitative research methods such as the interview is discussed, followed by an outline of methods used to ensure ethical practice in the research. The design of the interview is discussed next and this section concludes with a critique of the methodology and methods employed in this study.

3.1 Theoretical and Analytical Framework

In this section, (3.1.1) Critical Social Research and the Social Model of Disability and (3.1.2) Adaptive Theory are discussed.

3.1.1 Critical Social Research and the Social Model of Disability

This study is underpinned by the critical social perspective, which stems from Marx's conflict theory (assumption of structural oppression based upon social class) (Humphries et al, 2000). Theorists of feminism, racialization and disability (Barnes and Mercer, 1997) have used critical theory to develop an alternative perspective to explain the socially excluded positions of women, BME people and disabled people in society, and to re-structure these (Haralambos and Holborn, 1993; Giddens, 1997; May, 1997).

Critical social research is concerned with changing the production of knowledge and structural relations and therefore is more than describing the meaning people give to their social reality (Harvey, 1990). CSR involves deconstruction of given structures to reveal how these are oppressive to marginalised groups in society (such as women, BME people, disabled people, etc.), and reconstruction of these in the light of current knowledge, which should lead to political change (Harvey, 1990; May, 1997). As Harvey argues:

> *At the heart of critical social research is the idea that knowledge is structured by existing sets of social relations. The aim of a critical methodology is to provide knowledge, which engages the prevailing social structures. These social structures are seen by critical social researchers, in one way or the other, as oppressive structures (1990:2).*

The focus of CSR is upon structural analysis that relates to participants' social reality in wider structural and historical processes (ibid), rather than individualising them. For example, disabled people's exclusion from mainstream activities has been generally considered to be their problem (Barnes and Mercer, 1997), thus individualising disability.

An alternative view has been provided by the Social Model, which argues that it is how society is structured that prevents disabled people from accessing environmental, economic and political activity, because these are designed for the majority, who are non-disabled people (Oliver, 1990,1996a/b; Barnes and Mercer, 1997; Barnes et al, 1999). This framework has assisted with re-defining disability as a social rather than an individual problem and is widely used by disability activists and service providers. However, the Social Model has been criticised for concentrating on the common factor of disability discrimination and failing to acknowledge factors such as gender, ethnicity, sexuality, age and class which compound the social exclusion that disabled people experience (French, 1993; Stuart, 1996; Shakespeare, 1997; Vernon, 1997). As Cohen-Mitchell argues:

> *Your identity – your gender, race, class, ethnicity, sexual orientation, religion, urban versus rural, etc. – affects how you interpret the world. The multiplicity of identity leaves no room for the idea of a universal 'we' who might claim to speak on behalf of all women, or on behalf of all disabled people (2000:148).*

In CSR the participants' social reality is located within their respective social and historical contexts. For example, when considering South Asian parents' and their disabled children's access to service provision, there is a need to explore to what extent they face barriers related to their ethnicity and/or their children's impairment and the extent to which these inform service providers' policies and practices. According to Ahmad (1994):

> *historically, racialized minority groups have been thought in the west to be dangerous to their own health. Their cultures, lifestyles and genetic make-up have all been criticized for their presumed intellectual backwardness, ill-health and premature deaths (quoted in Ahmad, 2000:7).*

The focus of services has been to integrate BME people into the British way of life rather than providing appropriate information and services in which diversity is recognised.

3.1.1.1 Social change

Fundamental to CSR and the Social Model is creating social and structural change (Harvey, 1990; Oliver, 1997). For example, giving South Asian disabled young people and their parents an opportunity to define themselves and to be heard (Cohen-Mitchell, 2000; Rioux et al, 1997). This can be empowering (Vernon, 1997) and by raising their awareness of their social position within given social structures, might allow them to re-evaluate their interaction with these structures. A similar approach was used by Cohen-Mitchell (2000), who used critical literacy (raising awareness and conscientization) and participatory methods to enable disabled women in El Salvador to frame themselves rather than be framed by other people in society. As a result of raising their awareness disabled women *"...redefined themselves according to their own desires, needs and possibilities as women who were disabled"* (Cohen-Mitchell, 2000:148). However, Zarb (1997) argues that disabled people's participation does not necessarily result in their emancipation. Participatory methods should be about putting research skills at the disposal of disabled people, so that they have control of the research enterprise, including funding. This is problematic for South Asian disabled children and young people who are invisible and require allies (Moore et al, 1997) to promote their inclusion in the production of knowledge, from which they have been historically excluded. Consequently, their inclusion through participatory (Zarb, 1997) and emancipatory methods (Priestley, 1995, 1997; Oliver, 1997) is a process.

To include South Asian disabled young people in this research, I began by raising the awareness and praxis (reflection and action) (Harvey, 1990) of the South Asian parents who have control regarding access to their disabled children and therefore their participation in research. As a South Asian woman (researcher) I was aware that in some South Asian families bypassing the parents to communicate with the children is considered inappropriate and that the 'expected' procedure is that of approaching the parents first, thereby acknowledging their status as carers with responsibility for the well being of their children.

In terms of critical advances in childhood research, acknowledging different cultural practices that abound within groups and families is important when considering avenues through which children's views could be sought and heard. For example, in working with children with diverse ethnic backgrounds Keats suggests that:

> *Above all, respect the cultural values of the child's parents even when they differ from your own. You do not have to agree with them in order to show respect. Insincerity on your part will quickly become apparent, but a genuine effort to understand the child's relationship with the family culture and its expectations for the child will be rewarding in your dealings with the child and other family members as well (1997:69)*

In the light of my understanding, I approached the parents first to gain access to the children, in that way I both acknowledged their role in the decision-making processes and respected cultural 'norms'. The parents made it clear when the research purpose and process was explained that their children's participation depended upon their children's wish to do so.

The research process was de-mystified (Dockery, 2000; Whitmore, 2001) by explaining the various stages and by involving the parents in designing the data collection methods with their disabled children, which resulted in joint ownership between us, of the research design. This enabled a change to occur regarding the perception of South Asian parents about their disabled children's ability to express their views and their right to information. The research has helped parents to construct a way in which their disabled children's views could be sought both in research and practice (service planning), thus improving the quality of their lives. The parents might request service providers to communicate directly with their disabled children regarding service provision and not through them. The parental interviews revealed that the there was reluctance to inform their disabled children about relationships, marriage and related issues because they assumed that their disabled children might not be able to comprehend such concepts.

However, through discussion at the group interview (see chapter 3, section 3.2.4.2), the parents realised their disabled children's right to make informed choices about these issues for which they required support and information at home. Participation in the group interview also extended the parents' contact with other parents who might have similar experiences to them. By allowing access to their disabled children and therefore their participation in this research it enabled the following outcomes for the disabled children/young people (which would have not been possible had access been denied):

- A raising of self-esteem of South Asian disabled younger people by listening to their views. Most people feel valued when they are asked directly about their opinions about various aspects of their lives, rather than seeking these through colleagues, friends and family. Similarly the disabled young people in this research felt valued (Vernon, 1997) because they were *talked to* rather than *talked about*. This was evident by their engagement in the interview where, for example, the majority talked about previous and forthcoming events in their lives. One participant did not want the interview to end and another wanted the interview to end but continued to chat.
- Increased familiarisation of South Asian disabled young people with research and consultation processes. Their participation in future research initiatives will not be a new or different experience because of a familiarity with the process gained through their participation in this study.
- Extending contacts of both the parents and disabled young people. Disabled children and young people, particularly those who attend special schools and structured activities, interact with a limited pool of people. The disabled young people who participated in this research were invited to a fun morning along with their siblings to meet their peers, other siblings, parents and professionals who they might not otherwise meet. The methods used for data collection are discussed later in this chapter.

3.1.1.2 Political Commitment

The principles of CSR require political commitment in CSR research to explore social structures and to uncover whether and how social structures experienced by participants such as South Asian parents and their disabled children are oppressive. According to Harvey:

> *For critical research this means that an analysis of oppressive social structures is in itself a political act (1990:23)*

CSR expects that social change should occur in the lives of the participants, in this case South Asian disabled young people and their parents, as a result of the knowledge that is examined and is generated from the research (Harvey, 1990). This makes the research political because it is aimed at uncovering mechanisms that are dominant and showing what is happening at a societal level and is *"...also concerned with doing something about it"* (Harvey, 1990:20). For example, disseminating findings of the research to the participants, policy makers and service providers would inform them about the social barriers experienced by South Asian disabled young people and their parents in accessing mainstream life and services. Harvey argues that:

> *Critical social research includes an overt political struggle against oppressive social structures (Harvey, 1990:20)*

As a South Asian woman I have subjective experience of racism and therefore started from an assumption that South Asian parents and their children also experienced racism due to social structures that are oppressive (according to my experience). Thus conducting this research was both subjective (because of my experience of racism) and also political (because I was engaging with social structures that I assumed to be oppressive) and therefore both of these aspects influenced the research design – for example the use of CSR that requires political commitment to enable social change by challenging 'taken for granted' assumptions.

Researchers are social beings and are often part of the societies that they investigate and therefore cannot strip away their values at will to conduct value-free research (Denscombe, 2002). As Denscombe argues:

> *While it might be understood that researchers cannot ever be totally objective (by working without the influence of concepts, language or social values), good research should continue to strive towards objectivity as far as possible under the circumstance (2002:171).*

Denscombe suggests that researchers take account of the following broad themes to register their particular perspective:

- Acknowledge vested interests and sponsorship, which might compromise the findings.
- *"Be clear about their social values".*
- Add a short biographical note to inform readers of possible interests in the topic and how this might have influenced the research.
- Question their own assumptions and perceptions, which might require them *to "...suspend common sense temporarily and to stand back from what they 'know' as a normal person in society to look at things afresh, like a stranger".*
- *"Engage with the views held by others, even those whose beliefs or activities the researcher might regard as wrong"* (2002:171).

These themes have been considered in the relevant sections in this research, for example a biographical note has been provided in chapter 1, and is elaborated below to illustrate the affinity that I shared with participants, which impacted upon the research.

Affinity

As a South Asian woman (with a hidden impairment) I shared one or more of the following aspects with the participants: ethnicity, language, gender, age, being an immigrant, a sibling and a daughter. Thus I had 'partial identity' with the participants, for example with some of the South Asian mothers, I shared experiences of racism and sexism, and being perceived generally as passive

and dominated in our own communities (Bhopal, 2000). However, I also recognised differences that were influenced by our access to education, employment and services (Bhopal, 2000). As Bhopal states:

> *Partial identification' means we also recognise that which separates us, such as forms of oppression that might be rooted in such traits as skin colour, language and education. In these appearances, we see a manifestation of power relations according to which the whole of society is structured (2000:73).*

Partial identification can lead to shared experiences and empathy with participants (Woodward, 2000), but it can also cloud what researchers 'see' as significant to the research (Bhopal, 2000).

3.1.1.3 Non-disabled researchers doing disability research

Disabled people (Branfield, 1998; Hunt, 1981) have called for disability research that transforms the lives of disabled people rather than furthers the careers of researchers, particularly non-disabled researchers. Miller and Gwynne's study (1972) 'A Life Apart', regarding The Le Court Cheshire Home (a residential home for disabled people) is a prime example of research that benefits the researchers rather than the participants (disabled people in the home). Miller and Gwynne (social scientists at the Tavistock Institute, London) were approached by some of the disabled residents in the home including Paul Hunt to conduct a piece of research which they thought would support them with their struggle to represent their views in the management of the home, engage in shared decision-making processes and have greater control over their lives (Hunt, 1981). Miller and Gwynne were funded by the Department of Health to conduct a pilot study regarding segregated institutions (ibid). However, Miller and Gwynne's study (1972) whilst acknowledging the oppression disabled people experience recommended improved training for staff within the institutions so that the residents could be better cared for because they were considered (by Miller and Gwynne) to need to remain in the institutions till their death. The researchers benefited from the study as the book published as the result of it was one of the key books for the Open University course *"'The*

Handicapped Person in the Community'" (Hunt, 1981:38), and they were also commissioned by the Department of Health to conduct another research project. The disabled residents however did less well because Miller and Gwynne's study (1972) re-enforced the view that disabled residents in institutions were there because they were unable to care for themselves and therefore required to be cared for (disability was linked to inability to be independent). This perception was illustrated by the recommendation for improved training for staff so that they could take better care of the residents whilst they were in the institutions (which was till their death), rather than ways in which disabled residents (and people) could be supported to live independently in their own accommodation. The Miller and Gwynne (1972) study highlighted the mechanisms through which prevailing attitudes about disability (that the impairment limits participation rather than social barriers) socially exclude disabled people from controlling their lives and participating in mainstream life. However, non-disabled researchers committed to changing the social relations of disabled people can contribute to making disabled people's voices heard in academia, social policy and practice. As Hunt argues:

> *Whether they are from amongst the ranks of physically impaired people ourselves, or from amongst others who seek to help our struggle forward, social scientists committed to ending our oppressive situations are the only ones who can look straight at reality – not those who are mainly on the lookout for technically interesting theoretical and practical pay-offs (1981:43)*

As a non-disabled critical social researcher conducting disability research, I used the following six features of emancipatory research as identified by Stone and Priestley (1996) to make this research inclusive:

- *the adoption of a social model of disablement as the epistemological basis for research production*
- *the surrender of claims to objectivity through overt political commitment to the struggles of the disabled people for self-emancipation*
- *the willingness only to undertake research where it will be of some practical benefit to the self-empowerment of disabled people and/or removal of disabling barriers*

- *the evolution of control over research production to ensure full accountability to disabled people and their organizations*
- *giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences*
- *The willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people (Stone and Priestley, 1996:706).*

The application of the above features is illustrated throughout this research, for example adoption of the Social Model, underpinned by CSR. However, the aspect of *"evolution of control over research production"* was not achieved because South Asian disabled younger people and their parents are generally an invisible group in society and therefore difficult to access. The time that would have been required to build a trusting relationship and empower disabled young people and their parents to participate in the decision-making process of the research would have been prohibitive in a time related limited research project such as this. However, having built a relationship with the disabled young people and their parents, and familiarised them with the research process, I will be able to draw upon them in future research initiatives.

The features of emancipatory research suggested by Stone and Priestley (1996) were further reinforced by meeting the key principles of gain, empowerment and reciprocity emanating from Oliver's (1997) emancipatory paradigm, as explained below.

Gain

Ultimately, I gained research skills and in-depth knowledge about disability, and secured employment in which I was able to apply theory to practice and make services inclusive to disabled children/young people. For example, by:

- Promoting service planning that is grounded in disabled young people's views (at the Multi-Agency Disabled Children's Co-ordination Project).
- Using the Social Model in practice by relating disability to social barriers.

- Raising awareness of the social exclusion that is experienced by disabled young people and BME disabled young people and ways in which they could be included at seminars, conferences and lectures (of future practitioners).
- Disseminating findings through seminars and conferences by using the participants' experiences.

Empowerment

The disabled young people gained by being able to express their views by themselves, which is a liberating experience (Barnes, 2001), particularly for those who have historically been silent. As mentioned previously, the disabled young people's self-confidence increased because they were listened to (Vernon, 1997).

The parents were enabled to disclose their feelings about having disabled children without feeling guilty for harbouring feelings that were often negative. Parents were also enabled to reflect upon existing practices that focus upon disability rather than the environmental aspects that prevent their disabled children's participation in mainstream activities, which can be empowering. For example, I ensured that support was in place at the fun morning for disabled children who required this so that they could attend. One parent did not wish to bring her child because she felt he might be disruptive and I convinced her that support was available and therefore she should not exclude her child from participating.

The service providers were able to talk about their services and also the tension that existed between their personal views and the expectations of their services.

Reciprocity

The research was reciprocal in the following ways:

- South Asian parents: were provided with an opportunity to talk about having disabled children; sign posted to organisations that might be able to help and given an information pack containing information about services that

were available nationally and locally. I answered their questions (Oakley, 1981, Vernon, 1997) and exchanged personal information including my home telephone number so that they could ring me to cancel pre-arranged interviews if required, which some did.

- South Asian disabled young people: I answered their questions, which were sometimes personal, and gave them the videotape of their interview after the research was completed. Prior to data collection with the disabled young people I found out about organisations that provided services such as counselling, if required by participants as a result of talking about their experiences.
- Service providers: were given information and recommendations from my professional experience of working with South Asian communities and disabled children. For example, one service provider requested information regarding support groups for South Asian parents with disabled children and another about how to improve their services to meet the needs of BME disabled children.

Friendship

Vernon (1997) in her study regarding the experiences of Black disabled women developed long-lasting friendship with some of her participants, which continued after the research. In contrast Bhopal (2000) decided to maintain a professional relationship with the South Asian women in her study because she felt that friendship between the researcher and participant could cause confusion to the goals of the research. Bhopal (2000) argues that participants could perceive the researcher as an expert who has answers to all their queries and thus false expectations could be raised. In this research I had a cordial relationship with all the participants and have a friendly professional relationship with one of the participants because we are both involved in the field of disability. Although participants revealed personal and sometimes intimate details about themselves, none of the participants indicated an interest to develop a friendship outside the research relationship and therefore my interaction with the other participants, outside the research, is minimal.

I decided that I would acknowledge the participants, if I meet them outside the research environment, and leave any possible further interaction to them. Thus they would have control about extending contact if they wish (Vernon, 1997).

Summary

Critical social research underpins this research because it requires the researcher to go beneath 'taken for granted' assumptions about participants' social reality, thus uncovering how social systems and structures manifest the oppression that is experienced by South Asian disabled young people and their parents because of racism and disability. The framework of the Social Model provides an alternative way of viewing disability in which external structures are 'blamed' for preventing disabled people from participating in mainstream activities rather than impairment. The principles of emancipatory research practice enabled me to make the research as inclusive as possible. In the next section, I discuss the analytical framework that assisted with data analysis.

3.1.2 Analytical framework

The analysis of this study was assisted by adaptive theory (Layder, 1993, 1998) and underpinned by critical social research and the Social Model.

3.1.2.1 Adaptive theory

> *The word 'adaptive' is meant to convey that the theory both adapts to, or is shaped by, incoming evidence while the data itself is simultaneously filtered through, and is thus adapted by, the prior theoretical materials (frameworks, concepts, ideas) that are relevant to their analysis (Layder, 1998:5)*

Adaptive theory (Layder, 1993, 1998) allows data to be analysed flexibly to maximise theory generation. The following tenets of adaptive theory (discussed below) made it a more relevant and better method to assist with analysis and theory generation for this study:

- Multi-methods and strategy is used to maximise theory-generation.
- Analysis and theorizing is ongoing rather than a discrete part of the research process.
- Prior theory and knowledge is used to assist with data analysis.
- Participants' social reality is related to general theory and wider social structures, and thus power relations are explored.
- Data is treated flexibly by going back and forth, between emerging data and other sources to generate theory.

In developing adaptive theory Layder (1998) combines and modifies elements of Merton's (1967) middle range theory and Glaser and Strauss's (1967) grounded theory to provide a flexible approach to theory generation. For example, Layder (1998) argues that both quantitative and qualitative approaches could be used to generate theory, whilst Merton's middle range theory favours quantitative approaches to that of the qualitative and Glaser and Strauss's grounded theory focuses on theory generation from emerging data.

According to Layder, adaptive theory:

> *...falls somewhere between what are variously referred to as 'theory-testing' or hypothetico-deductive approaches on the one hand, and grounded-theory (or theory-constructing) on the other (1998:132)*

The table below outlines the main differences between adaptive theory and grounded theory.

Table 3: Adaptive theory and Grounded theory

Adaptive theory	Grounded Theory
• Use of general, substantive, prior, existing, extant and emerging theory in data generation. • Allows data to be linked to wider social structures and social relations that influence participants' social reality. • Pre-coding leads to provisional coding which is open to reformulation through going back and forth and therefore regular re-examination of the data • Emerging data is not discarded but revisited as necessary to aid theory generation.	• Focus on using emerging data for theory generation. • Prior theory is not used at all – research approached as a 'clean' slate. • Prescriptive techniques and procedures for coding data: open, axial and selective. • Focus on generating as many codes as possible from empirical data leading to conceptual codes and confirmation of core codes. • Unselected data is not open for revision resulting in this data being discarded.

3.1.2.2 Multi-methods and strategy

Adaptive theory allows use of a range of methods (in this study qualitative methods: semi-structured and telephone interviews were used – discussed further in chapter 3, section 3.2.4) and strategies to generate theory and is commensurate with CSR which is not restricted to the use of any one method, but those that are relevant to revealing oppressive structures and enabling change (Harvey, 1990). In adaptive theory, the principle is 'openness' to the use of resources such as *"...general and substantive theory, theory testing types, sensitizing concepts, and empirically emergent theory"* (Layder, 1998:43) to maximise theory generation. The aim is discovery that should be systematic yet flexible and able to deal with issues that arise in the research.

However, an unstructured eclectic approach is not used (Layder, 1993). What is expected is a disciplined use of methods and strategies (such as the tenets mentioned above) together with other methods and theories to assist with theory building and validity (Layder, 1998). Although a multi-method and strategy approach lends itself to triangulation, which is viewing the data from different angles through use of various methods, which assists with the validation of data (Burgess, 1984; Layder, 1998; Seale, 1999; Siraj-Blatchford and Siraj-Blatchford, 2001b), the focus is upon theory building (Layder, 1993).

3.1.2.3 Analysis and theorizing is integral

In adaptive theory, analysis and theorizing is on going, thus acting as an integral rather than a discrete part of the research process (Layder, 1998). For example, analysis and theorizing takes place as soon as the idea for research is mooted, which is followed by research activities in which decisions are made regarding funding, purpose of research, topic, and research design, which is influenced by the theoretical perspectives of the researchers. For example, the considerations made prior to embarking upon this research included funding, and purpose, which was to contribute to research material regarding the experiences of South Asian disabled young people and their parents and to enable change in their lives.

Thus, on-going theorizing involved a development of an understanding of the position of South Asian disabled children and adults in the production of knowledge, which appeared to be of social exclusion. A starting point for their inclusion was making their voices heard, in the production of knowledge. Consequently, the CSR approach and the Social Model influenced the research design.

3.1.2.4 Prior knowledge

Adaptive theory allows analysis of emerging data (the participants' social reality) to be conducted with the use of prior knowledge, general and substantive theory, and emergent data. Prior theory (extant theory and data) is knowledge that is known about the research subject and includes research material, documents and the researchers' experience (Layder, 1993, 1998).
This assists with analysing emerging data with prior and existing data, which allows these to be confirmed, refuted and/or developed, which aids theory generation in light of existing knowledge. For example, I used my experience of working with South Asian parents with disabled children to inform my practice, such as viewing South Asian parents as having knowledge about their disabled children and interdependent relationships with them (Ahmad, 2000; Atkin et al, 2000). Adaptive theory embraces both subjectivity and objectivity, and it advocates the exploration of the participants' subjective experience of their social world and their interaction with wider social structures, from an *"...objective observer's point of view..."* (Layder, 1998:140). Denscombe (1998) suggests that researchers provide their biography so that their possible influence upon the research can be assessed.

In adaptive theory, deductive and inductive procedures are used for analysis. In terms of inductive analysis the ideas, themes and questions emerging from the data are used to guide the analysis and theory generation (Patton, 1990). Prior knowledge and theory is used to guide the data and concepts that are used to sensitise the process of data generation and analysis (Patton, 1990; Layder, 1998).

Layder (1998) argues that it is not necessary to use the terms used by participants to define their situation, because researchers can conceptualise this (via prior and existing knowledge) within a wider context, which might not be part of the participants' understanding and therefore vocabulary. This does not mean that new data is 'fitted into' existing knowledge, rather the new data is used to transcend existing knowledge, which ensures that the data is not changed or invalidated by using prior and existing data. According to Layder, using extant theory, data and emergent data, enables creation of *"...a dynamic synergy between new thinking and accumulated knowledge"* (1998:32).

3.1.2.5 General theory and connection to wider social structures

Adaptive theory generates middle range theory, which focuses upon the 'here and now ', social reality of participants. Layder's (1998) position links with CSR, which requires a connection to wider social systems and structures to uncover aspects of domination and power. This includes historical analysis of how inequality and oppression is constructed and reproduced through social systems and structures (ibid). For example, non-disabled people's control of decision-making processes, which exclude disabled people's own views, but affect their lives, because they are considered incapable of making decisions for themselves (Finkelstein, 1991). Thus a wider analysis of external influences that shape participants' experiences (Layder, 1993, 1998) is conducted, which fits with CSR's focus upon structural analysis (Harvey, 1990) because social structures are assumed to be oppressive and participants' social realities are explored in relation to how these affect their experiences.

In adaptive theory, general theories provide a background concept to assist with understanding the phenomena under investigation. In this study, general theories such as critical theory, and theories regarding racialization and disability, and specifically the framework of the Social Model, were used to understand South Asian disabled young people's and their parents' interaction with social structures and how power permeates social relations and structures.

According to Layder, general theories

> *...tend to be quite abstract and deal with general features of social life, such as the nature of the ties between power and social practices or the links between social action and social structures (or systems) (1998:40)*

In adaptive theory substantive theory that is specific to the subject under investigation is used. For example, existing knowledge about disabled young people (theories about disability and children and young people) and South Asian parents of disabled children (theories about disability, racialization and carers). This assists with analysing participants' social reality within their own social context (Layder, 1998), as well as broader contexts, which should result in knowledge that enables change to take place in the interaction between service providers, the South Asian disabled young people and their parents.

3.1.2.6 Going back and forth - treating data flexibly

Adaptive theory allows for going back and forth in the analysis, which enables reflexivity, the data to be revisited, and themes to be reformulated as ideas develop and new themes emerge. This fits with CSR, which according to Harvey:

> *...Is about a shuttling back and forth between concepts and data, structure and part, past and present, theory and practice, involving a continual process of conceptualisation (1990:201)*

In this process data is not discarded at any stage of coding and analysis but is used as a resource to be revisited, which allows ideas to be reformulated and developed (Layder, 1993; 1998). Flexibility in adaptive theory also allows the data source to be revisited as required, for example, the South Asian parents (data source) were revisited during the group interview, to clarify and develop data, which emerged from the interview data. The data coding process involves analysis of data at a preliminary stage. The table below illustrates the process of data coding in this study, which is subsequently explained further.

Table 4: Stages of data collation, coding and analysis with use of Word copy and paste facility

Stage	Task
1	Transcribe interviews – make copy Create a file for each participant Save relevant interview transcription and/or notes in the computer file
2	Create a new computer file Collate (copy and paste) responses to each question Move responses to relevant questions Write words, notes or questions in margins
3	Read through several times for data familiarisation and identification of key themes Annotate and/or highlight key words/phrases – initial in vivo codes. Data is read throughout the research process, as relevant
4	Open copy of collated file. Copy and paste relevant data under appropriate in vivo code and/or category Number code/category
5	Refer to existing literature, knowledge and conceptualise in vivo codes and categories Create sub categories and discussion points
6	Shift between categories, naming, renaming and reducing these, as they are refined. Look for relationship between categories.
7	Write up findings and analysis – reflectivity and refining goes on.

3.1.2.6.1 Data coding

Data coding and preliminary analysis began with reading the transcriptions and notes for familiarisation of the data and to identify key themes and words. The data was annotated in the margins with words, questions and thoughts as they occurred at that time (Layder, 1998). Some words and/or sentences were also underlined. At this stage, this was exploratory and done without direction to categorise the data, which in adaptive theory is pre-coding (Layder, 1998). The idea is to be open to new data being coded as the transcriptions and notes are read (many times) throughout the research process.

Identification of key themes was made easier by grouping responses under relevant questions, which were summarised, for example: *How did you find out about your child's condition?* to '*Finding out'* (Patton, 1990:376). This collated information was re-grouped under relevant in vivo codes such as *'looking after'*,

and key themes as they emerged and developed. The responses were coded with the interviewee's code and/or pseudonym, interview number, page number of the interview transcript and/or notes of the original, so that the information could be found in the original data if required, for example: *quote* N1, 1, p2.

Prior and existing knowledge (Patton, 1990; Layder, 1998) was used to:

- Review literature to assess emerging categories and findings with that of other similar studies in the field (Blaxter et al, 1996).
- Assist with conceptualising the categories (Layder, 1998). For example, *'social isolation'* conceptualised Asian parents' description of being unable to go out or feeling that they did not want to, which resulted in isolation. Patton refers to this as *"...sensitizing concepts [which] are concepts that the analyst brings to the data"* (1990:391).
- Point to significant themes that were emerging from the data, which reduces the need for generating large numbers of codes (Layder, 1998). In this study, translating the aims of the study to analytical questions, as illustrated in the table below, helped to manage the data, make relationships between themes and analyse the data.

Table 5: Aims of study translated to analytical questions for data management and analysis

Aims of study	Aims turned into analytical research questions (relationships between themes)
To explore the experiences of South Asian parents of disabled children, including their access to service provision by statutory and voluntary organisations	• What are South Asian parents' experiences of having a disabled child and how are these experiences shaped and why? (What forces are at play?). • What are South Asian parents' experiences of diagnosis and service provision, and does this influence their view of disability and their interaction with their child including their future (how and why?).
To explore the experiences of South Asian disabled children and young people	• What is the relationship between the role of parent (carer), child and intervention (diagnosis/services), in shaping children and young people's experiences? (What shapes these experiences, how and why?). • What is the relationship between interaction with parents, intervention and the child's perception? What models are used in this interaction, how and why?
To explore service provision for South Asian parents of disabled children and young people and how service providers perceive South Asian disabled children and their parents	• What is the relationship between the perception of South Asian parents, disabled children and service provision that follow? (Are South Asian parents and children required to fit into the status quo and are services geared to meet their needs? Is there understanding of their needs and how is this demonstrated?). • What are service providers' perceptions of South Asian parents of disabled children? Is there a relationship between perception and the services that follow?

Pre-coding led to provisional coding in which initial, reformulated and new codes were confirmed as key themes for further analysis, which were open to revision if it aided theory generation.

Data coding and analysis by computer

In this study, the Word package was used to assist with data coding and categorisation, as illustrated in table 4. This helped with data management by creating files for the data of the three groups of participants and themes as they developed. The copy and paste facility in Word also assisted with grouping and regrouping data under relevant themes as these were developed.

Computer packages that attach codes to data and link themes to illustrate relationships between themes are available such as NUDIST and Atlas-ti (see Fielding, 1993 for a comprehensive list). These packages are able to organise (code, file and retrieve) greater volumes of data quickly and efficiently than is possible manually and also link data and create relationships for analysis (Dey, 1993; Richards and Richards, 1998). However, these were not used because learning to use a computer package from scratch would have taken up valuable resources in a time limited project such as this, in which the Word copy and paste facility was found to be sufficient for my data management and analytical needs. As Fielding argues:

> *...depending on the amount of data you have and the depth of analysis you want, it might make sense to use The Ethnograph, or a word processor and outlining software, or revert to highlighting pens and Post-It notes. The overhead in setting up and using packages is not always worth it (1993:3)*

The copy and paste facility in the Word package was also useful with familiarisation of the data and also to see patterns and themes as they emerged through grouping data together or shifting data from one place to another. This enabled me to highlight certain words and make notes of questions that arose, which are a form of memo writing (Layder, 1998) that assists with analysis.

It also enabled me to leave the original data intact, which is an important principle of CSR as it allows the original data to be revisited if required.

3.1.2.7 Reliability and validity

Reliability and validity were achieved by:

- Achieving consistency in the research approach as illustrated in chapter 3, section 3.2.4. This 'audit trail' (Denscombe, 1998; Seale, 1999) shows the procedures that were followed for data collection and recording of data, including field notes, to add rigour to the fieldwork. Denscombe argues that reliability *"...entails an evaluation of the methods and techniques used to collect the data"* (2002:100). The evaluation of the methodology and methods used to conduct the study (chapter 3, section 3.2.7) show that this was appropriate for researching South Asian disabled children and their parents.
- The data was verified by re-visiting the transcripts and notes (Sarantakos, 1998) at each of the coding stages (mentioned above) to ensure that the data was grouped in the appropriate codes and categories, and to avoid moving data out of its original context.
- The emergent data from which in vivo codes were derived and conceptualised was substantiated by existing literature (Denscombe, 2002). For example, the data regarding the parents' experience of concern about their disabled children is substantiated by Katbamna et al (1998) and Read (2000).
- Member validation (Seale, 1999; Denscombe, 2002) was conducted. For example, the participants' responses were checked during the interview, by repeating their responses and/or my notes (where notes were taken) back to them. The interview data from the parents' interviews was presented to them in a group interview for their validation, as stated in chapter 3, section 3.2.4.2.

Saturation

The empirical validity of the data was supported by the information, from which in vivo codes and categories emerged (Melia, 1997). For example, the in vivo code of *concern* was supported by the parents' interviews in which the majority of the parents expressed their worry about their disabled children, regarding various aspects of their lives. This includes their worry about their children's impairment, future, care, education and participation in life, compared with their non-disabled peers. The conceptual category of *improvement* was also well supported by the parents' interview data. For example, the majority of the parents hoped that their disabled children's impairment would improve so that they could participate in life like their non-disabled peers. This, along with concern, particularly about care in the future, was a recurring aspect in the interviews, and thus both concern and improvement were saturated by the interview data, as was the other data (Melia, 1997).

Summary

Adaptive theory, used in this study for analytical purposes, made a better approach for theory generation, because adaptive theory allowed the use of a multi-method and strategy approach to both data collection and analysis, thus creating flexibility. Adaptive theory allowed data analysis with the use of emergent data (participants' social reality) and prior, general and substantive theories to test existing theories and develop new theories. Participants' social reality was also linked to wider social structures to understand how domination and power is manifested through social systems and structures, which shape South Asian disabled young people's and their parents' experiences. This fits with CSR and the Social Model's principle of the production of knowledge that enables change. In the next section I discuss the research methods and tools that were used to conduct the study.

3.2 Research Methods and Tools

In this section the rationale and details of the research procedures that were employed in this study are presented in the following sub-sections:

(3.2.1) Overall design of the study

(3.2.2) Sample

(3.2.3) Identification and access issues

(3.2.4) Research tools

(3.2.5) Ethical practice

(3.2.6) Design of the interview schedules

(3.2.7) Critique of methodology and methods employed.

3.2.1 Overall Design of the Study

This study was conducted in five main stages and each stage informed the planning of the next, as illustrated in the table below and subsequently explained further.

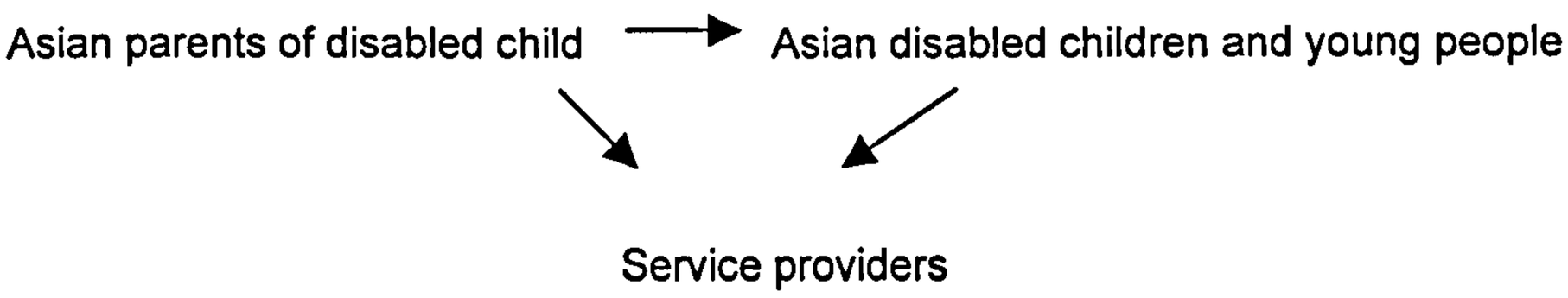
Table 6: Stages of research

Stages	Research work conducted
One: Consider and confirm participants for the research. Recruit South Asian parents	Preparatory work: • Design criteria for participants • Consider process of the research • Consider strategies for recruiting participants • Identify and contact key services • Design and distribute flyers about the research • Submit articles in newsletters/magazines
Two: Data collection with South Asian families	Preparatory work: • Consider methods – in-depth and repeated interviews, participant validation meeting. • Design interview schedule • Arrange and conduct interviews • Gain consent to their disabled children's participation
Three: Data collection with South Asian disabled younger people Participant validation meeting with parents and activities with disabled children and siblings	Preparatory work: • Confirm consent from parents/professionals and the young people • Consider methods – semi-structured in-depth interviews • Design interview schedule • Organise support as required • Arrange and conduct interviews • Preparatory work for meeting and activities • Conduct meeting with parents and activities with disabled young people
Four: Data collection with Service Providers	Preparatory work: • Consider methods – telephone interviews • Design interview schedule • Select services • Contact these and confirm consent to participate • Conduct telephone interviews
Five: Data coding, analysis and writing up.	• Compile information for writing up and complete writing up.

The first stage: South Asian parents and their disabled children as well as service providers (statutory, voluntary and community) were confirmed as the relevant groups from which data would be collected for this research. The views and experiences of each of these groups were regarded as vital to constructing a holistic picture of the impact of interaction between these groups, and would also assist with validity through triangulation (Burgess, 1984; Layder, 1993, 1998; Denzin and Lincoln, 1998b; Seale, 1999; Siraj-Blatchford and Siraj-Blatchford, 2001b). The rationale for selecting the sample is provided in chapter 3, section 3.2.2.

Semi-structured in-depth and repeated interviews with South Asian parents were conducted first, so that rapport could be built up with them (Taylor and Bogdan, 1998), to help with gaining consent for their disabled children's participation and subsequent access to them. Additional information was also gained which helped with planning semi-structured, in-depth interviews with disabled children and young people. Information from both these groups assisted with designing the interview schedule for telephone interviews with service providers. This provided a bottom up approach to data collection as illustrated in figure 1 below.

Figure 1: Bottom up approach to data collection



South Asian disabled younger people and their families are generally invisible in society (CIO, 1987). Therefore access was gained through key services, which generally establish databases of the people to whom they provide services. Six South Asian parents were recruited through this strategy and a further seven by talking to a support group for parents.

The second stage: The interview schedule for South Asian parents was designed and semi-structured in-depth interviews were conducted. Eleven South Asian parents were interviewed. Out of the eleven, 8 participated in a repeated interview resulting in a total of 19 in-depth interviews (11+8=19), which were conducted between February 2000 and March 2001. The interviews ranged between 20 minutes and 1 hour in length, with an average (mean) time of forty-four minutes.

All the parents were married at the time of the interview and were living with their spouses, apart from one who had separated from her partner and was

living with her maternal family. Two were living as part of a joint extended family (with the husband's parents) and three on their own with their children. All the disabled children had siblings. The ages of the parents ranged from 20 to 45 years. Census categories were not used during the interviews with South Asian parents, because they were provided with an opportunity to define themselves rather than be defined by given categories. The majority described themselves in terms of religious categories and some also added ethnicity as illustrated in the table below:

Table 7: Background of the South Asian parents

Background	Parent's definitions	Number of responses	Total
Hindu	"Hindu/Indian"	2	5
	"Hindu"	3	
Muslim	"Pakistani Muslim"	1	5
	"Gujarati Muslim"	2	
	"Indian Muslim"	1	
	"Kutchi Muslim"	1	
Punjabi	"Punjabi"	1	1
Total			**11**

At the time of arranging the interviews, parents were informed about the purpose and process of the interview and research as well as issues of consent and confidentiality. Any requirements for interpreters, alternative venues to their home and transport also were checked and provided if required. I interviewed seven parents in Gujarati (including the use of some English words by all of us) and three in English and employed an interpreter to assist with an interview in Punjabi.

The third stage: The interview schedule and method of data collection for South Asian disabled younger people (7-18 years old) was designed. I was aware of my limited experience of working with disabled children with cognitive and communication difficulties and sought advice from my supervisor – George Taylor, Robert Orr (consultant - disabled children with cognitive and

communication difficulties), Meg Jones (consultant and writer - early years), and relevant professionals who were familiar to the children and their parents.

The rationale for conducting data collection with children/young people aged 7-18 years was informed by the following:

- The UN Convention defines a child as *"every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier" (Unicef:2).*
- Historically, children's competence and comprehension to make decisions has been determined by age-related maturity. However, age-related definitions are problematic and inappropriate for children with disabilities. Moore et al, (1998:75) argue that for *"non-disabled babies, infant status ends as they become physically independent ..."*, whereas many disabled people are dependent on other people often throughout their lives. Hence they are defined by *"labels of infancy* ", resulting in loss of power to control their lives (ibid). Despite a blurred boundary between childhood and adulthood, children's ability to comprehend disability and/or illness and to deal with this has been illustrated by research. For example, Ireland and Holloway's study highlight *"children's representation of asthma"* (1996:160) and Atkin and Ahmad's (2000) research show black young people's awareness and management of sickle cell/thallasaemia. However, Ireland and Holloway argue that:

> *Children between seven and 12 are generally considered to have attained the stage of concrete operations which means they have an understanding of events and behaviour that they have experienced themselves, and which have direct relevance for them"* (1996:160)

Ireland and Holloway also argue that *"School age children are usually more able to articulate and describe their experiences..."* (1996:157) and they suggest that if possible, older children rather than younger children should be preferred for involvement. In light of the above, the age criterion regarding the involvement of disabled children and young people in research is 7 - 18 years of age.

Seven South Asian disabled younger people participated in semi-structured interviews. Out of the seven, 3 participated in repeated interviews resulting in a total of 11 semi-structured interviews, which were conducted between May and July 2001. Some participated in more than one setting and one person was interviewed three times (7+ 3 + 1 = 11).

A group interview with the South Asian parents took place on 2nd February 2002, in which the main themes emerging from their interviews were presented and validated as an honest reflection of their experiences (appendix 5). Clarification about their views concerning marriage of disabled people and their awareness of recent disability legislation was sought. An informal evaluation of the meeting and research approach was also conducted (discussed in section 3.2.4.2). A fun morning was also organised for the disabled young people and their siblings, to meet together and extend the pool of people with whom they have contact.

The fourth stage: Service providers were selected using the criteria (appendix 1) and an interview schedule designed. The interviews with the South Asian parents and young people identified the services that intervened significantly in their lives, as well as those that intervened irregularly or not at all, such as Social Services. Local community groups that were used by some of the parents were also identified. This information, along with the criteria, helped to select service providers for data collection.

Twenty-two representatives from statutory, voluntary and community organisations participated in telephone interviews, which took place between February and July 2002. Some of the providers were those contacted at the start of the project and others were either representatives of these services or other services, which were selected at the time of data collection.

The majority of the statutory providers who were contacted at the start of the research (stage one) offered support as requested, although some suggested a central point of contact within the respective local authority, thus reducing the number of services that could be contacted. Some of the service providers hinted at being very busy and/or involved in other research initiatives, thus indicating that the method of data collection required careful consideration to ensure participation. Consequently some of these service providers were sent a letter outlining the following options for data collection: workshop, semi-structured interviews or postal questionnaire. However, at the time of the data collection with service providers, telephone interviews seemed appropriate because of their geographical location.

In total, 19 interviews were conducted with the South Asian parents, 11 with South Asian disabled young people and 22 with service providers resulting in 52 interviews, as well as a group interview with the South Asian parents and a fun morning with the South Asian disabled children/young people. The interviews ranged between 20 minutes and 1 hour in length, with an average (mean) time of forty-four minutes.

Table: 8 Number of interviews with the participants

	South Asian parents	**South Asian disabled young people**	**Service providers**	**Total number of interviews**
Length of interviews:	*45 minutes – 1 hour*	*20 minutes – 1 hour*	*20 minutes – 1 hour*	
1st Interview	11	7	22	40
2nd Interview	8	3		11
3rd Interview		1		1
Total	**19**	**11**	**22**	**52**

The fifth stage: Involved the collation and analysis of the information and data that was collected during the research to write a comprehensive dissertation. Layder's (1993, 1998) adaptive approach was used to assist with the data analysis (discussed in chapter 3, section 3.1.2).

Summary

In this section the research process, which was conducted in five main stages, was briefly explained. Research tools that were used and issues that arose during the research were referred to, which are elaborated in the subsequent sections.

3.2.2 Sample

In this section, the rationale is provided for purposefully selecting the sample, using theoretical sampling from an adaptive theory approach (Layder, 1993, 1998).

3.2.2.1 Theoretical sampling

Theoretical sampling from an adaptive theory approach was used to purposefully select a sample which comprised South Asian parents with disabled children, South Asian disabled children/young people and service providers (statutory, voluntary and community organisations) from six Local Authorities. This is because it allows the participants' reality to be connected to wider social systems and structures, and prior theory (general, substantive and extant theory) as well as emergent data to be used for sampling purposes. Thus resources are used holistically to inform the selection of participants for theory building.

The South Asian disabled people's inclusion in mainstream life and activities depends upon how they are supported by their parents and service providers. The key issue here is the nature and extent of the parenting support received by South Asian parents, as this will have a major impact on their ability to fulfil their caring and mediating role (between services, other individuals in society and

their disabled children) and hence provide the support that their children/young people need. The type of support they receive and the language in which it is couched will also affect their understanding of the impairment and influence the way in which they interact with their disabled children, service providers and the wider society. How services providers' perceive South Asian parents and their disabled children also has an impact upon the services that they provide to this group. This is because services are designed and delivered by service providers who are informed by personal, social and political structures. Quinn argues that:

> *In working with families, many social workers and rehabilitation professionals assume that other people share their cultural views regarding concepts such as appearance, functional ability, success and death (1998:xviii)*

South Asian disabled young people's experiences and interaction with other people is influenced by how impairment (functional limitation) and disability (social exclusion) is perceived by their parents and service providers. For example, if parents and service providers focus upon impairment as the limiting factor in disabled children's participation in mainstream life, rather than social barriers, then it individualises this particular aspect as the 'problem' for the children. Therefore it was crucial to understand the interaction between these three groups because each group's perception about the other influences their interaction, and any change that might occur in one is likely to have an impact upon the other.

3.2.2.2 A purposefully selected sample

Non-probability sampling such as purposive sampling was used to select participants from the three groups. Purposive sampling according to Sarantakos enables the researcher to:

> *...purposely choose subjects who, in their opinion, are thought to be relevant to the research topic. In this case the judgement of this investigator is more important than obtaining a probability sample. The process of sampling in this case involves identification of the informants, and arranging times for meeting them (1993:138)*

Purposeful sampling is useful when researching groups such as South Asian disabled young people and their parents whose numbers are generally unknown (Layder, 1998).

Therefore probability sampling such as "*Simple random sampling* where each member of the population has an equal chance of being selected" (Siraj-Blatchford and Siraj-Blacthford, 2001a:155) was considered inappropriate, because it is based upon numbers that are known of the sample within the general population. Ethnic monitoring data from Special Educational Needs statements and from Social Services Departments was considered inappropriate for sampling purposes because it seemed that there was no consistent approach to recording the ethnic backgrounds of service users. For example, at the beginning of this study one statutory provider informed me that their service did not have any South Asian children as service users, and another informed me that they did not record ethnicity but information could be gleaned from the recorded names of the children. The service providers' data in chapter 6 suggests that not all the 22 organisations that participated in this research monitored the ethnic background of their service users.

Random sampling techniques, such as use of postal codes and telephone digits (ibid) in which participants are selected at random from the general population, could not have been used because the numbers of South Asian parents with disabled children is uncertain within the South Asian, disabled and general population. Random sampling claims to be representative of the general population whilst purposive sampling does not and can lend itself to smaller samples.

However, findings cannot be generalised wider than the sample group (Siraj-Blatchford and Siraj-Blatchford, 2001a), although purposive sampling allows data to be gathered from different groups (ibid) of participants such as South Asian parents, South Asian disabled young people and service providers, which could increase understanding of how they perceive disability and racism.

The adaptive theory approach to theoretical sampling (Layder, 1993, 1998) advocates selection of samples that are informed by empirical data as well as prior and existing knowledge. For example, I was aware through my employment at RNIB and also personal experience that South Asian parents with disabled children are less likely to come forward to participate in research, because in doing so they are likely to draw attention to themselves as being parents of disabled children and therefore experience the discrimination that their disabled children experience. The South Asian parents might fear repercussions from services if they make their views known about the services that they receive and their understanding of the concept of research might also deter them from participating in it (Begum, 1992).

My field experience informed me that South Asian parents with disabled children generally experienced isolation and often did not know other parents in a similar situation to themselves. In this study, those parents who attended parent support groups admitted to knowing other South Asian parents with disabled children. One parent informed me that another parent was going to contact me, but they did not do so during the research. Thus snowball sampling, in which the size of the sample increases as each participant identifies others that they might know in a similar situation to themselves, might not have yielded the number of (11) South Asian parents that purposive sampling had.

Purposive sampling offered the avenue of identifying South Asian parents and disabled young people through specialist disability services for disabled people/children and was considered suitable for selecting participants from the three groups.

The main variables used to select each group are stated below, further details are presented in the criteria in appendix 1:

- South Asian parents should be of South Asian background, reside within the six Local Authorities, use services and have a disabled child aged 0 – 18 years of age.
- South Asian disabled young people in addition to the above, should be aged 7 –18 years of age.
- Service providers should be located within the six Local Authorities and provide services to disabled people and children and/or BME communities, including South Asian communities.

The six local authorities were selected to complement the work of the RNIB South Asian Families Project, and will not be named in order to offer anonymity to the participants in this study.

Summary

In this section, I argued that selecting a purposeful sample by using theoretical sampling from an adaptive approach, was appropriate because this allowed the sample to be selected with prior, general and substantive theories as well as emergent data. A smaller sample might be limited in terms of numbers of participants and generalisability of the findings in a wider context. However, it can improve our understanding of how society treats South Asian disabled children and their parents. In the next section I discuss the strategies that were used to identify and access the participants.

3.2.3 Identification and Access Issues

South Asian parents and disabled young people were mainly identified through services that provide specialist support services to disabled children/people and their carers. Service providers were identified through colleagues, organisations and directories.

3.2.3.1 Identifying South Asian Parents

Numerous strategies were used to identify and access South Asian parents with disabled children as explained below.

Publicity and distribution of flyers

The study was publicised through newsletters and magazines such as 'RNIB Asian Families Project', Visibility, New Beacon and LOOK. The study was also publicised through a talk show presented by Midland Asian Television (MATV) (a free South Asian television channel, covering the Midlands region).

A4 flyers informing South Asian parents with disabled children were produced (appendix 2a and 2b). These were distributed:

- To Parent Partnership Officers in the six Local Authorities.
- To local libraries through central library services within the six Local Authorities.
- To local voluntary organisations through the Council for Voluntary Services in one Local Authority.
- At a local Asian Mental Health Awareness Day in a Local Authority.
- At a Mela (gathering) in a Local Authority.

However, the above initiatives in themselves did not yield any South Asian parents with disabled children as participants.

Presentations

The aims and objectives of the study were presented at a regional meeting of teachers of visually disabled children and at a Team Works course for Learning Assistants. At both of these meetings A4 flyers requesting assistance from professionals and services (appendix 3) were distributed along with the A4 flyers informing South Asian parents about the study. South Asian parents were not recruited through these presentations.

The above methods did not result in recruitment of South Asian parents as respondents because these methods were indirect rather than direct. Therefore there was reliance upon other people to inform the South Asian parents about the study. There was also an assumption (by myself) that South Asian parents of disabled children attend events such as the Mela, and/or that members of the South Asian communities would pass on information to South Asian parents and disabled members of their communities.

Contact with Services

Statutory (Education and Social Service Departments) and voluntary services were identified through the Education Yearbook and Social Service Yearbook 1997, and local and national directories. A formal letter (copy in appendix 4) was sent to the Directors of Education and Social Service Departments, and a local charity which provided services, within the six Local Authorities chosen for this study. A copy of the letter was also sent to Heads of relevant departments such as Sensory Services to inform as many relevant people as possible about the study. This resulted in eight South Asian parents indicating an interest to participate in the study. However, out of these, two parents were not contactable despite checking their details with the statutory service that had passed them on.

Six South Asian parents were interviewed. Five had visually impaired children and one had a child with cognitive, communication and mobility difficulties, which provided useful information such as the similarities and differences regarding their experiences of service provision and personal feelings. Consequently South Asian parents of children with cognitive, communication and mobility difficulties impairment were included. The processes of gaining support from specialist services was repeated, but it did not yield any further participants.

Talking directly to a parent support group

A talk about the study was given to a South Asian parent support group in a local authority, which resulted in five parents participating in the study. Talking directly to South Asian parents seemed to be the best approach to achieve response, but given the time and resource constraint it was not possible to conduct an extensive mapping exercise to locate parent support groups other than to ask existing services for this information. Local groups are often managed by charities and/or small voluntary organisations, which make access difficult because the person in charge is not easily identifiable. Events and visitors to some groups are booked in advance and therefore access to the group is dependent upon a 'slot' being available and can delay access. For example, numerous telephone calls over several months were made before I was granted access to the South Asian parents' group. Managers of local groups can also act as gate keepers, for example, I was not granted access to another South Asian parents' group despite several requests over a period of time and the manager's support for the study. However, seeking participants through support groups can lead to bias within the research because the sample could include a greater number of participants who are empowered to attend support groups. The reliability of the data obtained could be affected by the fact that the participants who provided it were not representative of a wider group of South Asian parents of disabled children. However, it does offer an opportunity to gain knowledge about the experiences of the parents regarding getting information about support groups, the difficulties with accessing these and also the benefits of attending support groups as well as informing about experiences of parenting disabled children.

3.2.3.2 Gaining access to South Asian disabled children and young people

The South Asian disabled children/young people were accessed through their parents, as key informants, because of their insight into their children's lives arising from their interdependent and reciprocal relationship with them (Ahmad, 2000; Atkin et al, 2000).

For example, parents have knowledge about their children's preferred methods of communication and characteristics such as being shy and inquisitive. This information was helpful because it allowed me to consider the most appropriate method of data collection for each disabled young person. For example, one parent informed me that her son was shy, particularly of women, therefore was unlikely to look at me and/or to respond to my questions. Therefore it was decided that the help of a facilitator, to whom her son was more likely to be responsive should be sought. Indeed during the interview this particular young person did avoid looking at me and consequently communication between us was mainly conducted through the facilitator (who also was a woman!).

South Asian parents were informed about the purpose and process of the research, the groups of participants, outcomes and limitations. Interviews with the South Asian parents were conducted first, which enabled me to build rapport and learn their views regarding their disabled children's participation in the research. This helped me to seek the parents' consent to approach their disabled children for their participation (Mahon et al, 1996). The parents were also informed that professionals who worked with their disabled children in a statutory establishment would be contacted for their views about methods that the children used in that setting. The parents agreed with this and gave contact details of the professionals to approach in this capacity. Apart from one parent who did not wish her child to participate, the majority of the parents were happy for their disabled children to participate if they wished. However, one parent was apprehensive at first about her child's participation and only agreed after the points about the research practice were re-iterated, and upon condition that consent was granted from a particular professional at the child's respective school. The research ethics applied in this case (and for all the younger participants) were:

- Use of child's preferred methods of communication.
- Ascertain professional opinion about child's preferred methods of communication.

- Use of facilitators that the child was familiar with to assist with communication.
- Consent from the child to participate.
- The interview would be stopped at any time that the child wished.
- Harm to the child would be avoided as far as possible.
- Aim to seek the disabled children and young people's views rather than relying upon the views of adults.

Seven disabled young people participated in the research. The information that South Asian parents provided about their respective children included preferred methods of communication, the questions to ask to elicit the information that was required, their personalities and details of the professional to contact at a statutory establishment. Thus parents were included in the research process whilst gaining access through service providers could have detached parents from this process.

Gatekeepers

Professionals can also gate keep access to participants, for example out of four professionals who were contacted for their support with data collection with disabled young people, one denied access for this purpose. This was because the professional felt that it was not in the best interest of the child to participate, in other words: 'what's in it for the child?'

3.2.3.3 Identifying service providers

A mapping exercise to ascertain the services that were provided to disabled people, children, and BME and South Asian communities was conducted. Information about local services and directories was sought from colleagues employed in statutory and voluntary sectors, and also from the information services located within the six local authorities and the Council for Voluntary Services (CVS), as well as the Internet.

Aspects that were considered to select a range of services included: size of the service; rural or urban location; specialist services (disability) or specific services (BME and South Asian) and statutory, voluntary, charity or community organisations. It was envisaged that five representatives from each local authority would be selected from services that comprised: statutory (education and social services), voluntary, charity and community organisations. This was because during my employment at the RNIB it seemed to me that various statutory and voluntary agencies provide specialist services to disabled children and their parents/carers, if they meet their criteria. Statutory specialist services include education and social services. In the voluntary sector there are the established charities such as RNIB, RNID, Scope, Mencap and also local voluntary organisations. There are also community organisations that provide services to particular groups such as BME groups. It was decided that because there was such a huge number of organisations that one from each group (education, social services, charity and voluntary organisation, and community group) would be selected from each of the authorities. The service providers were invited to participate in the research (appendix 11) and 22 organisations participated.

3.2.3.4 What worked and what did not work

The learning outcomes from the methods that were used to identify participants reveal that direct contact with potential participants is the best way of gaining their consent to take part. Indirect contact such as publicity and distribution of flyers was the least helpful way of identifying participants. Direct methods enabled the researcher to present the research purpose and process in terminology that was understood by different groups of participants and interact with them to clarify any issues that they might have. This is not allowed by indirect methods. Mapping service provision in order to select those for participation yielded useful contacts that could have helped with identifying South Asian parents with a disabled child, had this been conducted prior to contacting the services. The table below illustrates methods that worked and did not work.

Table 9: Methods of identifying participants that worked and did not work

Participant group	What worked	What did not work
South Asian parents	Direct contact with services Talk to parents via parent support group	Publicity Distribution of flyers via libraries, events, organisations. Presentations to professional/practitioners
South Asian disabled young people	Direct contact with their parents Direct contact with professionals	
Service providers	Mapping services Checking contact details Addressing letters to the relevant person Direct contact through telephone call to arrange meeting	

Summary

In this section, the process of identifying and accessing participants from the three groups by using different strategies showed that direct methods seemed to yield a better response than indirect methods. Next, I discuss the tools that were used for data collection.

3.2.4 Research Tools

In this section I provide the rationale for using qualitative methods such as in-depth semi-structured interview, telephone and group interview to gather data from the South Asian parents, disabled young people and service providers. I also discuss recording data and strategies that were used to achieve good research practice.

3.2.4.1 Qualitative methods

Layder's (1993, 1998) multi-methods and strategy approach for data collection allows a range of methods to be used for data collection to maximise theory-generation. A multi-methods approach refers to use of both qualitative and quantitative methods in the same research, however, in this study qualitative methods were used because they were considered more appropriate for the participants in this study (discussed further below). This fits with CSR, which is not restricted to use of any particular methods for data collection, but is open to use of methods that enable exploration of the participants' experiences within prevailing social structures (Harvey, 1990). This is because CSR places greater importance upon what is done with the data, such as creating social change, rather than the methods that are used to collect the data (Harvey, 1990). The use of a variety of methods allows the data to be gathered from different sources and viewpoints, such as South Asian disabled young people, their parents and service providers regarding the phenomena under investigation. Thus the data is triangulated (Burgess, 1984; Sarantakos, 1993; Denzin, 1998b; Seale, 1999), which assists with reliability and validity. Adaptive theory, whilst concerned with validity, focuses upon theory generation.

Layder (1993) argues that both quantitative and qualitative methods should be used where possible to build theory. However, in this study, qualitative methods were used for the following reasons:

- It is suitable for small-scale research with groups, which are not easily identifiable and accessible, such as South Asian disabled children/young people and their parents. My field experience informed me that to identify potential participants could be time consuming because of the sensitive nature of the study and the general invisibility of disabled children in society. Consequently, identification usually takes place through key services for disabled children, which does not necessarily yield the numbers of participants that are often required for quantitative studies, because participation is based upon access and consent from parents, carers, professionals and the participants.

- The positivistic stance of the quantitative approach for reliability through *"standardised"* (Taylor and Bogdan, 1998:9) procedures is also inappropriate when seeking the meaning participants give to their experiences, which are influenced by social and political structures, and amongst others life chances, social class, gender, age and disability. The quantitative approach was thus considered unrealistic and inappropriate for this study, which required an approach that was flexible, interactive and which considered participants' experiences within wider social and political structures.
- Theory is grounded in the South Asian disabled young people and their parents' social reality, because the data collected is rich with participants' accounts of their experience in their own words (Denzin and Lincoln, 1998a; Taylor and Bogdan, 1998). This allows construction of their *"own"* epistemology based upon their social reality (Collins, 1990: 202). This is important for pioneering research with South Asian disabled young people and their parents, where information about their experiences is lacking, because of their status as a minority within a minority.
- Methods can be determined by the interaction between the participants and the researcher (Denscombe, 1998). The researcher can decide and change the methods to suit the situation and/or can decide with the participant the most appropriate methods for data collection. For example I conducted an unplanned observation when an opportunity arose. I would have lost valuable insight regarding the interaction between other people and one of the participants, had I stuck to the intended methods that were initially chosen, such as the interview.

Qualitative methods include *"...questionnaires, interviews, documents and observation"* (Denscombe, 1998:7), which are useful for eliciting the views of participants about their social reality, as well as understanding their perception about their lives (Denscombe, 1998; Cannold, 2001).

Thus the richness and depth of the data offered by the qualitative method, such as the interview, rather than the breadth offered by the quantitative method (Denscombe, 1998) such as questionnaires, was considered a suitable method of data collection for the three groups of participants, which is explained next.

3.2.4.2 Interviews

Interviews allowed direct interaction between the participants and myself which was important to build the rapport that was required to elicit sensitive information (ibid), such as feelings experienced by parents when their children were diagnosed. According to Taylor and Bogdan:

> *The interview is a form of social interaction. It involves a face-to-face encounter between two-and sometimes more-persons, each of whom is sizing up the other and constructing the meanings of the other's words, expressions, and gestures (1998:98)*

Interviews allow interaction between the researcher and the participant in which questions could be clarified and participants could be probed for their responses (Cannold, 2001), which permits data generation.

In self-administered questionnaires this might not be possible because participants complete the questionnaire according to their understanding of the questions. Interviews can be individualised according to the situation that is presented at the time. For example, I was able to deal with the distress that some participants experienced as a result of revisiting their feelings at the time of their children's diagnosis, by listening to them. In telephone interviews with some services providers I was able to negotiate the responses that they wanted me to record due to the conflict they seemed to experience between their personal views and what was expected of them in their professional setting.

The interview was also selected as the main method of data collection because I could not assume that all participants communicated in the dominant methods of speech and English language (written and spoken).

I could also not assume the South Asian parents' literacy skills in English and their own languages, which are required for completing questionnaires. I therefore asked participants for their requirements and offered interpreters, translated information and alternative methods of communication and formats (for example, use of facilitators and large print) as appropriate, which could have been difficult if questionnaires were used. I also used the criteria set out by Denscombe (1998:111) to assess the suitability of the interview as the method of data collection, to elicit data which is based upon: feelings and emotions; sensitive issues and privileged information, as well as consideration of the feasibility of recruiting participants to interview and resources including time and cost to conduct the interviews. The table below illustrates the advantages and disadvantages between interviews, questionnaires and telephone interviews.

Table 10: Advantages and disadvantages of methods of data collection

Method of data collection	Advantage	Disadvantage
Interview	• Direct interaction with participants • Building rapport • Individualised interview • Can probe for information • Observable body language	• Time-consuming • Bias needs to be checked
Questionnaire	• Less time-consuming than face-face interviews	• Detachment from participants • Limited option to probe for in-depth responses
Telephone interviews	• Direct communication • Interviews with geographically spread participants • Cost and time efficient • Higher response rate because participant's body language is unobserved.	• Body language is unobservable • Information is not as detailed • Lack of access to the phone for a period of time

There are many types of interviews (such as: semi-structured in-depth interviews, telephone interviews and group interview) and for each group the most suitable type was used, as explained below.

Semi-structured in-depth interviews

Semi-structured in-depth interviews were used for data collection with South Asian disabled young people and their parents. This is because in semi-structured interviews the researcher uses a topic or interview guide to elicit information in areas of interest to them, without restricting the participants' responses and flow of information (Cannold, 2001).

Thus participants are allowed to *"...develop ideas and speak more widely on the issues raised by the researcher"* (Denscombe, 1998:113), as well as raising issues that are important to them (Cannold, 2001; Flick, 2002). For example the South Asian disabled young people wished to tell me about recent events that had taken place in their family, which were of interest to them. In semi-structured interviews the participants' responses might not necessarily correspond with the sequence in which the questions are asked, but ad hoc responses might be received in the flow of information which answer some of the questions that are to be asked (Cannold, 2001).

Semi-structured interview is one of the ways in which the in-depth interview is done (Minnichello et al, 1990). Taylor and Bogdan (1998) define in-depth interviews as:

> *...face-to-face encounters between the researcher and informants directed toward understanding informants' perspectives on their lives, experiences, or situations as expressed in their own words (1998:88)*

The researcher attempts to build rapport with the participants through frequent interaction leading to a deeper awareness of the participants' lives (Taylor and Bogdan, 1998). This is important for studies that investigate sensitive subjects such as disability and also for those that requires familiarisation with participants such as disabled young people. This is because disabled young people are vulnerable to exploitation due to disability and age, and therefore they might prefer to interact with people with whom they are familiar.

For example, I conducted three semi-structured in-depth interviews with Ajay (pseudonym) and by the last one I was becoming familiar with his method of communication and we were beginning to interact directly with limited intervention from the facilitator. In-depth interviews also enable the data to be checked during data collection (Taylor and Bogdan, 1998), and thus validated.

In-depth interviews with disabled young people and their parents enabled me to develop (over a period of time) an awareness of their social environment and the interaction between themselves and other people, which shaped their experiences of disability. Seidman argues that:

> *The job of the in-depth interviewer is to go to such depth in the interviews that surface considerations of representatives and generalizability are replaced by a compelling evocation of an individual's experience (1991: 42)*

According to Seidman, although individuals' experiences differ, the data might indicate a link between those *"...who are affected by common structural and social forces..."* (ibid), which can be seen by the reader. This can help counter criticism of the lack of generalisability allowed by interviews. Seidman argues that telling the story of participants' experiences might enable the reader to connect with these, resulting in them having an alternative view. This is important for raising awareness of the disability discrimination that South Asian parents and their disabled children experience and also that of the Social Model.

Rationale for using interviews with disabled young people

A review regarding research conducted with children and disabled children, suggests that a range of methods should be used for data collection, which are appropriate to children (Alderson and Goodey, 1996; Ireland and Holloway, 1996; Mahon et al, 1996; Beresford, 1997). Regarding disabled children, Morris (1998c), Atkinson and Williams (1990) and Connors and Stalker (2003), in their respective studies, used a range of creative and flexible methods which include: video, drawings-pictures, stories, poetry, computers, verbal/written information,

gestures, as well as focus groups, semi-structured interviews and observation. Children's perceptions differ from those of adults because of the (different) context of their respective social worlds (Beresford, 1997).

Therefore methods that are understood by adults might be inappropriate for children (and disabled children), who require methods that they are familiar with such as those mentioned above. Children are also a diverse group (Beresford, 1997; Moore et al, 1998), and therefore the methods of data collection need to be selected according to the needs and abilities of the child (Beresford, 1997; Morris, 1998c). For example, for children with cognitive and communication difficulties, the use of facilitators who the children are familiar with, is recommended (Morris, 1998c).

The South Asian parents and the relevant professionals suggested that the semi-structured interview would be the most suitable method of data collection with the disabled young people. Semi-structured interviews are time consuming because they can take between one to three hours and also because of the time that is taken travelling to and from the venue for them. Telephone interviews were considered inappropriate for both the South Asian parents and the disabled children/young people because the semi-structured interviews allowed observation of the participants' body language. For example, facial expressions and gestures used during the interviews. In the young people's interviews some of the young people nodded their head to convey a yes/no response.

Telephone interviews

Telephone interviews offer the opportunity to directly interact with participants to obtain their views as well as to clarify questions and probe for their responses, without face-to-face interaction. Telephone interviews also allow a greater number of interviews to be conducted in a shorter space of time (Lavrakas, 1993), which is relevant to this study, because I was going to conduct interviews with potentially 30 service providers.

Travelling time to conduct face-to-face interviews with these numbers of participants would have been prohibitive given the time constraint to complete the PhD. Therefore telephone interviews are resource effective and relevant for time-limited studies such as this, in which participants (services providers) are spread geographically within the six local authorities (Lavrakas, 1993; May, 1997).

In telephone interviews the observation of visual cues such as the participants' environment and body language that face-to-face interviews allow is lost (Frey and Oshi, 1995; May, 1997). This however, could encourage participation (May, 1997) because observation of body language and therefore possible judgement about the participant is eliminated. Emotions such as anxiety, boredom, excitement and hesitancy can also be gauged from the tone of the participants, which allows the interviewer to re-structure the questions and flow in order to extract the required information from the participants.

In telephone interviews participants can experience interview fatigue within 20-30 minutes of the interview starting (Lavrakas, 1993), and therefore the length of the interview requires consideration when designing the interview schedule. Participants (service providers) might also not wish to stay on the telephone line for more than 20 minutes, because it could hamper the day-to-day function of their organisation, particularly where there is limited access to other telephones. Therefore the duration of the telephone interview could inhibit participation, for example Burke and Miller (2001) found that potential participants withdrew when they were informed that the interviews would take more than 15-20 minutes.

Telephone appointments are also more likely to be broken than face-to-face interviews (May, 1997) and recording the telephone interviews could pose a challenge (Burke and Miller 2001).

Frey and Oishi argue that technological advancements such as:

> *Computer-assisted telephone interviewing (CATI) and computer-assisted personal interviewing (CAPI) make it possible for the interview to be completed with fewer problems of interview error (1995:6)*

However, investment in computer packages as well as learning how to use this can be costly and may not reduce the overall cost of using telephone interviews. Consequently, notes were taken during the interviews and the telephone interviews of those participants who consented to this were recorded for back up (Burke and Miller, 2001).

Group interview (for participant validation)

> *In this approach, interviewers bring together groups of people to talk about their perspectives and experiences in open-ended discussions (Taylor and Bogdan, 1998:113)*

For groups such as Ethnic Minority carers (Katbamna et al, 1998), group interviews provide an opportunity to meet and talk about their experiences. It also provides the researcher with data about the group interaction and experiences, and an opportunity to validate the findings with the participants in a group setting. For example, Papadopoulos et al (2002) presented reconstructed stories, from interview data, orally to participants in a group event. The stories comprised themes and sub-themes, and were discussed by participants in two groups, who confirmed these to be valid and thus the findings dependable. Papadopoulos et al (2002) argued that this enabled participant involvement and emancipation, and was an appropriate approach to validate data.

In this study, a group meeting with the South Asian parents, who participated in the research was organised, to validate the main findings from individual interviews, as an honest reflection of their views.

The main findings were presented in themes and sub-themes, which were stated on a flipchart in English and an Asian language, and A4 copies were given to participants (appendix 5). These were used to steer the group discussion (Flick, 2002) to the main findings regarding their experiences of being parents of disabled children. I facilitated the discussion and encouraged participation from all the group members in order to manage group dynamics, which are an important factor in group interviews, (Flick, 2002; Taylor and Bogdan, 1998). Participants generally confirmed the findings by saying, "*Yes*", nodding and/or engaging in short discussions, which was consistent with the information that they gave in the individual interviews and there appeared to be nothing that was different.

The attendees

Six South Asian parents (five women and one man) attended the meeting and two sent apologies. A parent of a disabled child (not a participant of the research) asked to attend the group interview, which was denied. This was because the interview was for the specific purpose of validating data from individual interviews with South Asian parents, which was confidential to the participants and thus not open to those who had not participated.

Alongside the group interview a fun morning was organised for the disabled young people and siblings to enable them to meet their peers and other people, and thereby extend the pool of people with whom they have contact. The purpose of the group meeting with the parents was to feedback the data from their interviews and also to collect further data if possible. To do the same with the South Asian disabled younger people would have been inappropriate because the interviews were tailored according to the individual's need and it would not have been possible to feedback information in a group basis. Interview data was checked with the younger participants at the time of the interview.

Five disabled young people (two female and three male) and three siblings including a relative (two female and one male) attended the fun morning. Seven volunteers (five female and two male) with a professional background in play and/or social care assisted with the fun morning. As far as possible volunteers were matched regarding gender, experience and the disabled young people's need for support. A volunteer also assisted with taking notes of the group interview, thus enabling me to concentrate on presenting the data and facilitating the discussion (Flick, 2002). The group interview was also audio-recorded for back-up purposes.

Outcome

The main findings that were presented were confirmed as an honest reflection of the South Asian parents' views. Clarification and information regarding their views about marriage concerning their disabled children and disabled people, as well as their awareness of the disability legislation (DDA 1995 and SENDA 2001) was also achieved. According to the parents the group interview met their expectations in the following ways:

- they were informed about the main findings of their interviews
- they were able to meet with other parents in a similar situation
- they were informed about new initiatives and legislation.

The disabled young people were able to meet with their peers and other people, which they enjoyed. This was evident in their engagement with other people and the activities that were organised. The majority of the parents said that their disabled children had enjoyed the event and one disabled young person asked if she was going there the next morning.

3.2.4.3 Recording data

The interviews were recorded by using one or a combination of the following methods: note taking, audio recording and video recording. Recording data, writing memos and field notes involves analysis and contributes to overall data for analysis (Layder, 1998). These aspects are explained below.

Note taking

Notes were taken of the interviews with South Asian parents and service providers. In the interviews with the South Asian parents, brief notes were taken of interviews that were audio-recorded and detailed notes of interviews that were not recorded. Detailed notes were also taken of the interviews with all the service providers.

In the interviews with both groups, verbatim notes (words and sentences) were taken where possible and where this was not possible my understanding of the response was checked with the participant. I also used my version of shorthand to note the data and found that note taking involves interpretation and analysis of data at an earlier stage (Minichiello et al,1990; Holstein and Gulbrium, 1997). The interview notes of the parents were written out in full after each interview to recollect as much information as possible (Minichiello et al, 1990).

Audio-recording

In face-to-face interviews, the use of a video recorder allows the researcher to observe non-verbal communication such as body language and facial expression (Atkinson, 1988; Minichiello et al, 1990; May, 1993; Sarantakos, 1993). This was particularly useful for the interviews with the younger participants. The interviews with 7 parents, 19 service providers and 2 young people were audio-recorded. All the interviews with the young people were video-recorded, in two of the interviews (one parental and one service provider) the audio recorder was stopped and re-started, as requested during the interview, when the participants did not wish the information to be recorded (Cohen-Mitchell, 2000).

The audio recorder was tested at the beginning of the interviews in order to avoid accidents resulting in loss of information (Burgess, 1984; Atkinson, 1988), which occurred in the first interview. The brief notes taken during the interview and my recollection of the interview were used to write the notes, which was checked with the participant in the repeated interview.

Consequently, I familiarised myself with the equipment that I used (audio recorder, video recorder and telephone recording connector) and tested these prior to each interview in order to prevent mistakes.

Transcription

The interviews with South Asian parents were transcribed soon after the interview. Some of the audio recordings of the interviews (with the South Asian parents, services providers and young people) were of poor quality. The audiotapes were replayed several times (Cohen-Mitchell, 2000) both on the transcriber and ordinary audio recorder and notes that were taken during the interviews (in case of such eventualities) were also used. The disabled young people's interviews were transcribed, and where the sound quality was poor, the respective videotapes (see below) were viewed (Flick, 2002).

The interviews that were transcribed were 'tidied up', by omitting repetitions and words, and adding words in brackets to make the statements (quotes) coherent. Nineteen out of 22 interviews with service providers were audio recorded to provide back up and also transcribed (although it was not possible to transcribe all the interviews because of the poor quality of the recordings). The notes taken during the interview were also used for collating and analysing the data.

Video-recording

All the disabled young people's interviews were video-recorded (with consent from them, their parents and professionals as relevant). Video-recording was used: to record (Faulkner, 1998) the disabled young people's interview so that their views, use of Makaton and gestures (their respective methods of communication) could be captured on tape and revisited as necessary; to give the participants a video of themselves. According to Faulkner *"Video can be used as a tool, a means to recall the maximum amount of information, like a Dictaphone or notepad"* (1998:89). Video-recording can also allow the researcher to revisit the interviews repeatedly at different times to check the data and retrieve quotes, in contrast to conventional methods (Flick, 2002).

Although Faulkner (1998) argues that the participants' reality at the time is captured, interpretation is based upon the viewer's perception (Flick, 2002).

Video recording assists with keeping the researcher's practice in check because this is also recorded and could be questioned by the people viewing the video. For example, the participants, parents, supervision team and Robert Orr (consultant), were informed about this. This raised issues of confidentiality and anonymity, which were clarified with the participants, parents, supervision team and Robert Orr. The intention is to return the video-recording(s) to the young people and their parents after the research has been completed. At that point they will be reminded about confidentiality issues and therefore to consider whether they wish to show this video to family members and friends.

Using the video-recorder

The video-recorder was, as far as possible, set up (on a tripod stand) before the interview in order to minimise distraction to the participants. Despite this, the young people were interested in the video and two were persistent that they wanted to see the video during the interview. Faulkner (1998) found that children and young people engage when video is used because they want to see themselves on the screen, and they have control, particularly when they are operating the video. At the end of each interview the video recording was replayed and the participant was given an opportunity to view their interview on the video-recorder and to operate it, which they seemed to enjoy.

Field notes

My field activity, views and methodological considerations were noted in personal logs, a working diary and my small book as illustrated in the table below. Burgess (1984) argues that taking field notes is an essential part of the research process, in which researchers' note their personal perceptions and experiences as well as methodological concerns, in order to reflect upon their research practice.

Table 11: Types of field notes taken in the research

Type of field note	What was recorded
Personal logs - kept after each interview with the South Asian parents and disabled young people (Minichiello et al, 1990).	• date of the interview, time, code, pseudonym as well as date when the log was written • observations, personal feelings, thoughts and opinions about the interview process, which helped me to reflect upon my research practice.
A working diary	• communication and activity that occurred on a day-to-day basis • date, name and/or initial of the person that I was communicating with • notes of the conversation/meeting • 'things to do' • agenda items for meetings/supervision.
My small book	• date of the entry, thoughts and ideas as they occurred during the research process.

Field notes provided valuable insight about my thoughts and reflections upon the research and helped with relationships between different interviews and data, as well as with data analysis at an early stage of the research, as the following extract from an entry in my small book illustrates.

> *26/10/0 – Looking at yp's data + Q.12 and also drawing upon what I remember of the data + interviews, it was interesting to note Re: Q.12 + marriage/relationships the responses of X about this + that it was her son who expressed wanting to get married + he also showed in my opinion sexual awareness. Perhaps I could have explored X's response further if I had the second interview with her after completing my meeting with her son – to get clarification about her thoughts. Perhaps this could be revisited at the group meeting.*

3.2.4.4 Achieving consistency in the interviews

Here I discuss how I aimed to achieve consistency and rigour in the interviews with the three groups of participants.

Arranging the interviews

South Asian parents and representatives of services who agreed to participate in the research were contacted via telephone to arrange a suitable date and time to conduct the interviews (Seidman, 1991). During this conversation the purpose of the study; aspects of confidentiality/anonymity; process and duration of the interview was re-iterated. South Asian parents were offered a suitable venue for the interview, transport and interpreters if required. The majority preferred to be interviewed in their homes with the exception of one, who was interviewed in my work place at the time. Prior to the interviews, South Asian parents were contacted via telephone either the day before or on the day, to confirm the interview. Service providers were informed that statistical information regarding the breakdown of their service users and members of staff would be required. Where possible the service providers were sent the relevant questions about statistical information prior to the interview via the post or e-mail. However, not all the service providers gave, or were able to give, statistical information (discussed in chapter 6).

The disabled young people's interviews were arranged in conjunction with their parents and/or professionals as relevant. Aspects such as time, venue, transport and facilitators were discussed with the parents and professionals, and suitable arrangements made. These were aimed at limiting the disruption to the young people's routines, for example, ensuring that the interviews were not conducted during classroom sessions, dinner and/or in place of a leisure activity such as a trip to the cinema. Consequently the interviews that took place at home were after school, or on a Saturday morning. The interviews with the young people were arranged through their parents and/or professionals rather than with them directly.

This could be because communication with the young people was through their parents and/or professionals and in future research practice direct lines of communication will be negotiated for direct access to the young people (Morris, 1998c).

Interview procedure

For all three groups, at the beginning of each interview, an interview procedure (Burgess, 1984) was used (appendix 6a, 6b, 6c), which assisted in achieving consistency of the interview approach. The interview procedure ensured that participants were informed about the purpose, process and possible outcomes of the research as well as the aspects of consent, confidentiality, and anonymity.

The interview procedure was used informally, flexibly and was a useful lead into the actual interview. However, achieving consistency of approach in the interviews with disabled young people proved difficult because each interview differed according to the respective young person's abilities and setting. For example, in the first interview with disabled young people, the disabled person began to ask me questions, before I could complete going through the interview procedure. I began by responding to his questions and then leading onto what I wanted to know. Thus aspects of confidentiality were not covered and there did not seem to be an opportunity to include this during the conversation. I was conscious of this and bore the responsibility of stopping the interview at any sign of possible disclosure of harm and dealing with this at the time (Mahon et al, 1996). In subsequent interviews with the disabled young people I ensured that I went through the interview procedure. Aspects of confidentiality were also clarified with facilitators who assisted during interviews with four of the disabled young people.

Dealing with interruptions

In all three groups, the telephone and/or people visiting interrupted some of the interviews. In this event the interview was stopped and re-started as soon as it was possible to do so.

In the telephone interview with service providers, I arranged to call them back soon after or at another convenient time and date, in order to continue the interview.

In some of the South Asian parents' and disabled young people's interviews, which were conducted at home, other family members were either present during the interview or interrupted the interview to see what was going on. In two of the interviews the siblings, as well as the disabled young people were present, which made asking parents about their feelings and experiences of having disabled children sensitive. This is because parents often express unhappy and negative feelings, which can have an adverse impact upon the disabled young person and their siblings. For example, Mr Raja (pseudonym) described his views regarding his child's impairment in the presence of his child and, at times, his siblings. Mr Raja informed me that his child got fed up of using the aids that he was prescribed; he was worried that his child might not be able to drive in the future and was concerned about his future education. He also tended to compare his child's behaviour with the other children. This might suggest to the child that there was something wrong with him, which was causing his parent anxiety.

The researcher's many roles

Other family members viewed me as a resource for information. For example, in one interview a family member asked me to look through a letter regarding welfare benefit, which I did. In the course of the research (and interview), the researcher is given and indeed can adopt many roles (Burgess, 1984; Bogdan and Taylor, 1998). For example Taylor, when writing a book about families, found that his relationship with *"...the Dukes..."* family developed over time, during which they informed him about various aspects of their lives and regarded him as an adviser and friend (Bogdan and Taylor, 1998:222). Consequently Taylor adopted the roles of adviser, lawyer and friend. Similarly, because I had conducted repeated interviews and had regular contact (via telephone) with the parents, it enabled them to share information about other aspects of their lives (Bhopal, 2000), rather than responding to my questions

only. For example one parent informed me of a family wedding and kept the photographs aside to show me. Another took me round her garden and with another I shared information about the vicinity in which we had resided at one time, employment and the countries from which we had immigrated. I found that I shared different aspects of my experiences and identity with the participants.

Summary

In this section, the appropriateness of using qualitative research methods for data collection with the South Asian parents, disabled young people and service providers was discussed. I argued that the interview, including semi-structured in-depth interviews, telephone interviews and group interview were relevant as methods through which to gather data that was rich with participants' accounts of their social reality. I explained that the interviews were recorded by taking notes, using the audio recorder and the video recorder as relevant. Field notes were kept, which enabled me to reflect upon my research practice and to contribute additional data for analysis. I illustrated how I aimed to achieve consistency and rigour in the interview and research approach. In the next section, I discuss how the research practice was ethical.

3.2.5 Ethical research practice

In this section I present the decisions which were taken that made the research practice ethical.

3.2.5.1 Power

As a critical social researcher, I started from an understanding that social structures including the production of knowledge could be oppressive (Harvey, 1990), thus I was engaging with prevailing oppressive social structures and could re-enforce the social oppression that South Asian disabled young people and their parents experience. The research relationship is based upon power, (Priestley, 1997; Bhopal, 2000) and researchers, due to their privileged position, access information that they might not be able to in other circumstances (Woodward, 2000).

Bhopal (2000) argues that researchers can walk away with data which they can present according to their interpretation of the participants' social reality, whilst the lives of participants often remain unchanged. However, I aimed to avoid the re-enforcement of the social exclusion those participants' experience by adopting inclusive methods that are underpinned by the principles of CSR and the Social Model. Thus the focus was upon enabling change in the lives of participants by using methods that are ethical. Aspects such as *"informed consent, confidentiality and risk of harm"*, were also considered to prevent the risk of harm to participants, as set out by De Montfort University's Human Research Ethics (De Montfort University, undated:3). The consideration of the aspects below demonstrates how this research practice was ethical.

3.2.5.2 Informed consent

The participants were informed about the research purpose, process, stages, limitations and what was expected from them, as well as the possible impact on their lives as a result of participation in the research (Denscombe, 2002). This can help participants to make informed choices to participate in the research and the information that they wish to divulge. The participants' understanding about the process was checked and consent confirmed (Cannold, 2001). Participants were informed that they could withdraw from the research at any time and were not obliged to respond to questions if they did not wish to.

Consent was sought from South Asian parents (and professionals as relevant) and their disabled children to participate in the research (Alderson, 1995; Alderson and Goodey, 1996; Ireland and Holloway, 1996; Mahon et al, 1996; Morrow and Richards, 1996; Ward, 1997). However, I was dubious whether some of the disabled young people had understood the purpose and process of the research, although they had consented to the interview. Begley (2000) conducted research with young people with Downs syndrome, whose understanding of the research process she doubted, and she suggests that:

> *...it is important to consider the information that children have the right to know and to consider their language limitation when deciding how best to communicate this information (ibid, 2000:104)*

I engaged support from facilitators, used terms that the disabled young people were familiar with, and was vigilant about their engagement in the research. I was prepared to stop the interview at any signs of discomfort and did conclude an interview with a disabled young person because I felt there was little engagement in the interview process and to continue would have wasted both our time.

I was careful how data that was gathered outside the interview was used, such as conversations with parents, throughout the duration of the research, because of my uncertainty of whether this was consented to or not. The South Asian parents might have been unaware that, as a researcher, I was continuously gathering information and any dialogue that they had with me was observed as part of the research process (ibid), and was thus open to analysis.

3.2.5.3 Confidentiality

Participants were offered the opportunity to conceal their identity, so that they were not easily linked to the information they divulged. This is because participants might fear consequences as a result of their revelations. For example, South Asian parents might be apprehensive about the response that they might receive if they are openly critical about the services that they rely upon. South Asian parents might also fear the perception of others, including the researcher, in light of their revelations about having a disabled child (Katbamna et al, 1998; Woodward, 2000).

In small-scale studies such as this, the potential of identifying participants is greater because there might be fewer people who fit particular scenarios. For example, South Asian parents with disabled children are a minority within a minority and describing a parent who might have three children who have cataracts in a given area could easily identify them.

Consequently, the only characteristics of the South Asian disabled children and young people that will be stated in this study are age and gender. Their specific impairments and experiences of disability will be described if relevant and as far as possible an attempt will be made for them not to be easily identifiable.

Participants were informed that information they divulged would be used as relevant for the purposes of the research which would include dissemination of findings through presentations, journals and newsletters as required. Other than my supervisors and Robert Orr the data about the young people would not be accessed by other people, and would be stored in a secure place.

Anonymity

Participants were advised that information, which could easily identify them, would be changed or omitted. Participants were also advised to indicate if there was any information they disclosed (during the interview) which they wanted omitting from the final data collation and analysis.

Two of the participants (a parent and a professional) disclosed some information that was not to be used for the research.

Pseudonyms

Pseudonyms were used for parents and disabled young people, who were asked to choose their alternative names, which most did. The pseudonyms were compatible with the respective participant's gender, ethnicity and religious background and thus their identities were not completely changed. However, changing names and descriptions does not completely protect identities as experienced by Woodward (2000), who felt angry and betrayed when her ex-therapist had written a paper in which slight changes had been made. Woodward (2000) was able to easily identify herself and concludes that researchers have the responsibility to ensure participants' confidentiality.

Privacy

Privacy was an issue when conducting in-depth interviews with parents at their homes and telephone interviews with service providers. This is because homes are often shared with spouses, children and kin, whilst workplaces are shared with colleagues and thus have the potential for other people being present during the interview and/or the interview being overheard. This was clarified with parents and service providers before commencing the interview. Service providers were also informed when colleagues entered the research office where I conducted the majority of the telephone interviews.

Respect

Although I disagreed with some of the terms used by participants such as *"Handicap"*, *"Mongol"*, and *"Coloured"*, I did not challenge this because it might be the terminology that participants were familiar with.

Sensitivity - dealing with distress

I was conscious that asking parents about their children's impairments might evoke feelings that they might have experienced at the point of diagnosis, which the parents might have to deal with at the end of interview, whilst I was able to walk away with the data (Bhopal, 2000). I was aware that South Asian parents of visually impaired children were rarely offered counselling when their children were diagnosed and required *"someone to talk to"* (Shah 1995:91). Whilst I did not offer counselling, parents were given an opportunity to talk about how they felt, rather than what they needed for their child - the focus thus was on them. Cohen et al (1992) recommend that parents should be given the opportunity to express their feelings and for these to be acknowledged by others. Consequently the interviews were conducted at the pace set by the parent, and I was prepared to stop the interview if the participant became too emotional and/or distressed to continue, which did not occur.

Support structure for the researcher

Research can be an emotional experience for researchers (Woodward, 2000) who require debriefing and support to deal with the emotion that can be evoked in the research process, as mentioned above. My support structure consisted of my supervisors and colleagues, who listened to me and offered advice, to deal with the emotion, distress and tension that is experienced by researchers during the research process.

The issue of Child Protection (children at risk of harm) was considered at the outset by the research team (my supervisors and myself). It was decided that any suspicion that I had regarding harm was to be reported to my supervisor (George Taylor) who would take the responsibility to deal with this. It was decided that I would deal with issues regarding disclosure at the time that this occurred, when I would inform the participants of the procedure: that would entail informing my supervisor about the disclosure resulting in possible involvement from relevant statutory bodies. I would also explain that it was important for me to do so as a researcher and citizen regarding the protection of children from risk to harm.

Boundaries

The relationship between the researcher and participants can change over a period of time due to familiarity and empathy (Bhopal, 2000) and therefore expectations can become blurred. To avoid this, a boundary was set at the outset regarding my role as a critical social researcher, which was primarily about enabling change in the lives of participants, through the process of research. Consequently, as an academic researcher my ability to provide counselling, advocacy and representation, which are often required by participants who are socially excluded in society, was limited. Instead, I familiarised myself with the available support and information services to signpost participants as required.

For example, I informed a parent about the services that are available, which reassured the parent about care for their disabled child in the future; I provided details of a national support group for a parent and details of local services and support organisations for another.

Dissemination of findings

Research findings are usually presented in academic and professional terminology and arenas such as conferences and journals, to which socially excluded groups such as people with learning disabilities (Ward, 1997) and South Asian parents of disabled children do not generally have access. Thus they are often unaware about how their views have been interpreted and represented. Ward argues that:

> *Now however, there is a recognition that people with learning disabilities are effectively disempowered by research if its findings are not accessible to them (1997b:41)*

Ward contends that the Joseph Rowntree Foundation has funded on-going services that disseminate information to people with learning disabilities that is accessible, for example through free magazines (ibid). In this research, the findings of the interviews with the South Asian parents were presented to them for their validation (chapter 3, section 3.2.4.2). An executive summary (appendix 7a, 7b, 7c) was sent to participants and access to the main study made available. Some of the parents had expressed an interest in this, which made it crucial that the study was in a language that was accessible and also met with the academic standard required (Priestley, 1999a).

Summary

In this section, I presented aspects that were considered to make the research practice ethical, to prevent risk of harm to participants as a result of their participation in their research. In the next section, I discuss the design of the interview schedules.

3.2.6 Design of the Interview Schedules

In this section, I explain the influence of the pilot, aim of data collection, language, age and sensitivity, upon the design of the interview schedules, which resulted in different types of questions and styles of asking questions between the three groups of participants.

3.2.6.1 Pilot of the interview schedules

The questions for the three groups of participants were piloted with colleagues. Their views were sought regarding the interview process, including the order and wording of the questions, difficulties in responding to the questions and length of the schedules (Sarantakos, 1993). In light of the comments that were received, the interview schedules were revised before using them in interviews with participants. The interview schedules were also kept in check by evaluating completed interviews and making changes as required.

A pilot of a sub-sample of South Asian parents and disabled young people was not conducted for the following reasons:

- The time involved in conducting a pilot could result in loss of participants through either loss of interest or change in their circumstances.
- South Asian parents/carers are generally reluctant to participate in research, because they do not wish to expose themselves as having disabled children, which is generally perceived negatively, which might have repercussions upon other members of their family (Katbamna et al, 2000).

Consequently, it was important to interview South Asian parents while they were still available. According to Harvey:

> *...all aspects of the research process are interrelated and all bear on each other. There is no neat linear sequence of events as the idealized research report format would have us believe...* (1990:208)

Aims of data collection

The aim of data collection for each group is stated in the table below.

Table 12: Aims of data collection

Participant group	Aim of data collection
Disabled young people	To explore the experiences of South Asian disabled children and young people.
South Asian parents	To explore the experiences of South Asian parents of disabled children, including their access to services provided by statutory and voluntary organisations.
Service providers	To explore service provision for South Asian parents of disabled children and young people and how service providers perceive South Asian disabled children and their parents.

Language

Language that participants were familiar with and likely to use in their daily life was used (Mahon et al, 1996; Denscombe, 1998; Dockery, 2000), so that the contextual nature of the interview could be understood by the participants and myself (Fontana and Frey, 1998). All attempts were made to avoid use of terms that were jargon laden, academic, and which individualised and medicalised disability, for example, the questions in appendix 8 (Moore et al, 1998).

Age

The views of disabled young people, South Asian parents and professionals were sought and the interview schedules were designed accordingly. This is because adult-related approaches to researching children and young people are inappropriate (Morrow and Richards, 1996) (discussed in 3.2.4.2)

The questions (appendix 8) were used as a guide (Burgess, 1984; Minichieollo et al, 1990; Booth and Booth, 1997; Moore et al, 1998). Broad questions such as: *How would you describe yourself?* were converted to: *Tell me a little bit about yourself? What you like?* The disabled young people revealed that they liked what their non-disabled peers liked such as music, going out and so on (discussed in chapter 5).

Sensitivity

I was interested in the disabled young people's views about relationships, marriage and associated issues such as safer sex and contraception, but I decided not to ask these questions (Denscombe, 2002) for the following reasons:

- Inappropriateness due to age, gender, culture and adult presence (myself, parents, relatives and professionals).
- Uncertainty about the disabled young people's awareness of such issues and support services that were available if required.
- The majority of the parents appeared not to have discussed these issues with their disabled children, which was highlighted in their interviews.

Consequently, it would have been irresponsible to raise the young people's curiosity about these issues, which their parents might have to deal with and might not be sufficiently informed to do so.

3.2.6.2 Types of questions

Open-ended questions such as: *How did you find out that your child has a visual impairment? Has finding out about your child's visual impairment made any changes to your life?* (Parental schedule, appendix 9a) allow participants to have control over the information that they divulge and a choice about how they framed their responses in their own words, rather than choosing a given category, which is a feature of closed questions (Minichieollo et al, 1990; Denscombe, 1998; May, 1997; Cannold, 2001). This is important for South Asian parents and disabled young people, because it allows them to describe their experiences of living in an ablist society (Rioux et al, 1997), in which their voices are generally excluded. In the absence of this, what is often heard is the researchers' representation of their views (ibid).

In-depth information about feelings, opinions and facts can be gathered by using probes in open-ended questions (Cannold, 2001).

For example, ascertaining South Asian parents' and societal responses to having a disabled child with the following probes: *How do you feel? How (do) your family, friends, relatives feel? How (are) you/your child viewed by other people?*

Service providers were asked questions (appendix 10) about services that they offered and models that they used to deliver these. Thus services were evaluated in terms of the range that were offered and whether they were meeting the needs of disabled children and their families, together with those from South Asian communities, as well as the impact of disability legislation.

The South Asian disabled young people were asked to describe what they liked and disliked in their lives. Therefore they, rather than the perception of other people (myself, parents, and professionals) framed their experiences, which is often the case (Rioux et al, 1997).

South Asian parents and service providers were asked questions regarding age, gender and ethnicity, to construct a picture about the participants and relationships between concepts such as caring and gender. However, these questions could be construed as personal, unimportant or challenging to participants and are generally asked at the end of the interview (May, 1997).

3.2.6.3 Styles of asking questions

Story-telling, recursive and funnelling approaches were used with the three groups of participants, because using the same approach would have been inappropriate given the aims of data collection and the characteristics of each group.

Story-telling approach

An informal story-telling approach (Minichieollo et al, 1990) was used to enable the South Asian parents to recount their experiences, which began with their response to: *How did you find out that your child has a visual impairment?*

This is because medical confirmation of impairment generally has a significant impact (Quinn, 1997) upon their lives. Story telling enabled the South Asian parents:

- To reconstruct their past experiences in light of their present knowledge, therefore the information divulged was not factual, but a representation of their past recollection (Booth and Booth, 1997; Thomas, 1999; Rioux et al, 1997).
- To talk about their experiences of living in a society in which disability is stigmatised.

Rioux et al, (1997) used a narrative approach in their study regarding violence and abuse experienced by disabled people in Canada. Thomas (1999) invited disabled women to tell their stories regarding their experiences of living with an impairment and/or disability as children, whilst Booth and Booth (1997) used narrative approaches to find out the experiences of adults who grew up with parent(s) with learning disabilities. In these studies participants were required to revisit past experiences and were provided with an opportunity to talk about stigmatised issues in a safer environment (Rioux et al, 1997), because these are not discussed openly in society.

Recursive approach

A recursive approach was used to interview the disabled young people because each situation and participant is considered unique (Minichieollo et al, 1990). This approach was appropriate because some young people were able to recollect their past experiences, whilst others (such as young people with cognitive difficulties) could recall their most recent experiences. Booth and Booth found that:

> *Informants who had less to say tended to be younger people (with or without learning difficulties) whose lives were still closely bound up with their parents or who, irrespective of age, had not yet fully negotiated the transition into adulthood (1997:137)*

Questions were asked flexibly and informally because the recursive approach relies upon the conversation continuing by linking a current remark with the next (Minichieollo et al, 1990). For example, in an interview with Ajay (pseudonym), before I could complete going through the interview procedure, he had begun to ask me questions.

A disadvantage of this approach is the likelihood of going off at a tangent (Minichieollo et al, 1990). However, this can be addressed by linking the conversation with the interview schedule (ibid). For example I asked Ajay about school (such as what he liked, did at school, etc.), when the opportunity arose during the course of the conversation.

Funnelling approach

A formal approach was used to ask questions of service providers, because their interviews were conducted within the context of their professional capacity regarding service provision, although, some service providers offered their personal views about their respective services as well.

A funnelling approach (Minichieollo et al, 1990) was used with questions to service providers, which began with: *Services offered: As mentioned during our previous conversation, my interest is in disabled children and families from Ethnic Minority (EM) communities, particularly South Asian communities. Could you please tell me what services you offer to this group of people? Could you please describe how services are offered?* These general questions about services led to specific questions about services to Ethnic Minority and South Asian disabled people/children such as: *Service provision for Ethnic Minority and Asian communities: In terms of offering services to Ethnic Minority/Asian users of services, what do you think are the issues involved in providing services that are appropriate to these communities? Do you think Ethnic Minority and Asian users of services, use the full range of services that are offered?* This allowed exploration of service providers' views regarding service provision to BME and South Asian communities (Ahmad et al, 2000).

However, asking questions about BME and South Asian communities can be seen as a criticism of professionals and/or service provision as identified at the piloting stage of the schedule. Therefore the service providers were eased gently into describing issues regarding service provision to BME and/or South Asian communities, which could sometimes make service providers defensive, if asked at the beginning.

Summary

In this section, I explained how the pilot, the aim of data collection, language, age, and sensitivity influences design of interview schedules. Consideration of such factors led to different types of questions and contrasting approaches to asking questions between the three groups of participants.

In the next section, the research methodology and methods that were employed in this research are evaluated.

3.2.7 *Critique of the methodology and methods employed*

In this section, the methodology and methods employed for researching South Asian disabled young people and their parents are evaluated in the following sections:

(3.2.7.1) Theoretical and analytical framework

(3.2.7.2) Research methods

3.2.7.1 Theoretical and analytical framework

Critical Social Research (CSR) (Harvey, 1990) was the overarching theoretical approach that underpinned this study. CSR assisted with the deconstruction and reconstruction of the South Asian disabled children/young people and their parents' experiences within a wider social and structural context. This involved exploring the taken for granted assumptions about South Asian disabled children/adults and their carers and the consequences of this upon them. For example, the South Asian parents' experiences (discussed in chapter 4) show that all the parents received support from members of their extended families.

However, some parents were well supported whilst others were not and might have required support from external sources such as support services. This could be inhibiting because of the general assumption (Flynn and Patel, 2002) within services that South Asian communities 'take care of their own' (CIO 1987; Shah, 1995; Atkin and Rollings, 1996; Watters, 1996; Qureshi, 2000; Mir et al, 2001; Flynn, 2002; Flynn and Patel, 2002).

South Asian parents of disabled children also experience disability discrimination in their own communities and the wider society (discussed in chapter 4). This can result in self-imposed and externally imposed isolation (due to disabling environments), and a lack of support from their families and social networks within their communities.

The under use of short-break services by BME and South Asian families with disabled children (Mir et al, 2001; Flynn, 2002; Flynn and Patel, 2002) is often considered by services to be because 'they prefer to care for their children themselves'. This might be the case for some parents but not all and the factors that inhibit BME and South Asian families from accessing short-break services include: culturally inappropriate services, lack of information about short-break services and lack of a flexible service (ibid).

The above examples illustrate that the deconstruction and reconstruction of South Asian disabled children and their families' experiences need to be considered within a wider social and structural context (Harvey, 1990).

Social Model of Disability

The Social Model of Disability (Social Model) provided the conceptual framework for examining society's treatment of disabled people (Oliver, 1990). The South Asian parents' and service providers' interaction with each other, and the disabled children/young people suggested that they generally used the individual (tragedy/medical model) of disability (defined in chapter 1).

The analysis of the South Asian parents' experiences (chapter 4) shows that the parents' perceived disability as inhibiting disabled people's participation in mainstream life compared to non-disabled people, rather than viewing societal attitudes to disability and inaccessible environments as preventing their participation. Consequently, the parents' considered a medical solution to the management of the disability (Oliver, 1990) which was to treat and/or rehabilitate the disabled person to fit into 'normal' life. For example, the majority of the parents hoped for their disabled children's impairment to improve through medical treatment and/or rehabilitation so that they could participate in mainstream life like their non-disabled peers. However, the South Asian parents' perception of disability is influenced by factors such as the media, society and intervention from services (Harvey, 1990). It is through this that the prevalent view of a disabled person as being incapable till they are like non-disabled people is maintained. For example, diagnosis conducted by the medical profession could result in labelling individuals as impaired (for example, as having a visual impairment – being blind or partially sighted - which suggests functional limitation to the processing of visual information), which in turn could result in suggested treatment and/or rehabilitation (through specialist services) to correct them. The general message is that disabled people need to be like their non-disabled peers to be part of the status quo, which is desirable, whilst being disabled is not, as illustrated by Rajan (South Asian disabled young person), in chapter 5.

The South Asian parents and the disabled young people in this study were generally unaware of the Social Model, and that a disabling environment prevents disabled people's participation in mainstream life. However, the use of the Social Model in this study was effective in raising the parents' awareness of an alternative approach to the individual (including the tragedy/medical and rehabilitation) models of disability. For example, a discussion with the parents regarding the importance of seeking disabled children/young people's own views about their lives resulted in the majority consenting to their children's participation (if they wished) in this research.

The process of including disabled children's views demonstrated to the parents that this could be done and could be applied in other areas of service provision and decision-making processes.

Harvey argues that:

> *The activity of engagement is at the root of further development of knowledge* (1990:21)

By informing the South Asian disabled young people about the research and giving them an opportunity to represent themselves, by providing views about their lives in this study shows that the Social Model could be applied flexibly to South Asian disabled children/young people and their parents. This fits with the principle of the UN Convention on the Rights of the Child (1989), that all children have the right to information (Potter and Whittaker, 2001; Willow, 2002).

The process of including South Asian disabled children/young people counters the criticism that the Social Model might be inappropriate for some South Asian disabled people, because of its focus upon attaining disabled people's independence to control their lives (Ahmad, 2000; Atkin et al, 2000; Hussain et al, 2002; Bignall et al, 2000a/b). This is because in some South Asian communities, the relationship between disabled people and their carers is considered to be interdependent (Ahmad, 2000; Atkin et al, 2000; Mir et al, 2001). Consequently, independence is seen as a western and alien concept (Ahmad, 2000). However, the Social Model advocates disabled people's inclusion rather than exclusion in decision-making processes that affect their participation in mainstream life (Oliver, 1990). For some disabled people it might involve independence from other people (usually non-disabled people) and the opportunities to make decisions about their own lives. For others, such as some South Asian disabled people, it might involve negotiated management of their lives. To the black disabled young people in Bignall and Butt's study, independence meant having *"...choice and control in their lives"* (2000a/b).

This is fundamental to the Social Model, which advocates for the inclusion of disabled people in all areas of life.

This research met the commonly held principle of CSR, the Social Model and emancipatory research - that research with disabled people should create social change in the lives of the participants (Harvey, 1990; Moore et al, 1997; Oliver, 1997; Priestley, 1999; Truman, 2000). The social changes that occurred in the lives of the disabled young people and their parents are stated in chapter 3, section 3.1.1.1 and summarised below:

- The disabled young people and their parents' experiences were made visible and their voices heard through presentation of the research at seminars, conferences, lectures, and in planning of services for disabled children/young people in Leicester, through the Multi-agency Disabled Children's Co-ordination Project.
- Perception of the South Asian parents that their disabled children can express views about their lives if they are asked and supported to do this, rather than the prevalent view that they are unable to do so.
- Increasing the self-esteem of the disabled young people by asking them their opinions and listening to them.
- Increasing the familiarisation of the disabled children and their parents to the research process, by seeking and enabling their participation in the research.
- Extending the contact that disabled children and their parents have with other people (disabled children, parents, and professionals), rather than the usual pool of people with whom they may have contact.

Adaptive theory

Data analysis was conducted with Layder's (1993,1998) adaptive theory, which allowed flexibility and use of prior, existing, substantive and emergent data for analysis and theory building. For example, substantive theory regarding disability and racism was used to understand the experiences of South Asian disabled children/young people and their parents in British society.

Adaptive theory also analyses the relationships between emergent data (participants' experiences) and wider societal structures, according to Layder:

> *The realist approach to fieldwork encourages the researcher to look for aspects of power in the data. The researcher should be aware of the different forms of power relationships and the resources on which they are based (1993:207)*

Layder (1993) argues that power and domination can be covert in the daily interaction between the participants and wider structures. This requires the researcher to understand how power and domination manifests in society and influences people's lives. This fits with CSR, which requires analysis of social structures *"...and its ideological manifestations and processes"* (Harvey, 1990:19). The South Asian parents' experiences show that their relationship with the services and professionals that intervened in their children's lives was based upon their knowledge and resources. For example, services and professionals gave parents the information that they felt they should have about their children's impairments and services. This resulted in the parents having some but not all the information regarding their children's impairments and the services that are available. The professionals used their knowledge and status as service providers (specialist and support services) to control the parents' and their disabled children's access to resources. This impacts upon the support services that the parents and children receive and could hamper their inclusion in mainstream life.

3.2.7.2 Research methods

Interview

The interview as the main method of data collection was effective in allowing the participants to talk about their experiences in their own words, as evidenced by the interview data. However, the learning outcomes, stated below, emerged from the research and interview approach, and will be considered in future research practice.

Interviews with disabled young people

The disabled young people's interviews were arranged with their parents and/or professionals at their convenience (Morris, 1998c), rather than with the young people. In future research with disabled young people, I aim to approach the disabled young people (with consent from parents and professionals as required) for their consent and to arrange for their participation at their convenience.

This study provides a platform for other researchers to undertake research in the future with disabled children/young people with cognitive and communication needs by considering methods such as data collection over a longer period of time, which should allow time to:

- build relationships with the participants
- become familiar with the participants' methods of communication thereby allowing direct communication between the participant and researcher, rather than relying on a facilitator
- conduct observations of the participants in a wider range of settings.

Video-recording the interviews

In the interviews with the disabled young people, the video-recorder was operated and controlled by me, rather than the young people. On reflection, it would have been more participatory if the young people had been supported to operate the video-recorder. Faulkner (2000) suggests that control to operate the video and record their views gives young people a voice. This is demonstrated by the 'Ask Us' video that was produced by a group of disabled young people, who were given control to video-record their views about their experiences (Willow, 2002).

Telephone interviews with service providers

The telephone interview proved to be suitable for data collection with the service providers.

This could be because of their familiarity with this mode of communication, which is generally used in professional practice. The interview schedules (rather than particular questions) could have been sent to the service providers prior to the interviews, which could have prepared them to respond to the questions. Burke and Miller, argue that:

> *Participants need time to reflect and think about their responses, and we have found that this padding of time ultimately yielded more thick, rich descriptive data from participants (2001:3)*

This will be considered in future research.

Group interview and fun morning for participant validation

The use of adjoining rooms to conduct the parents' group meeting and disabled children/young people's fun morning was disruptive. This was because the wooden partition, which separated the rooms, was opened and shut during the morning by one young person, which interrupted the parents' group discussion. In future greater consideration will be given when selecting venues for research purposes.

An informal evaluation of the research approach was conducted with the parents. They were happy with the research approach and said that it did not require improvement. One parent, in particular, appreciated being asked for her consent and opinion regarding her daughter's participation in the research. The parents' appreciation of the research approach (informing them about the purpose, stages, limitation and their involvement such as the group interview and their children's participation) was validated by their engagement in the research (Cannold, 2001). This was demonstrated by the parents' participation in the repeated interviews, the group interview, and their consent for their disabled children's participation in the research and attendance to the fun morning.

Identification and Access Issues

Although a brief mapping exercise of services was conducted at the beginning of the research, an extensive mapping exercise could have helped with identifying specialist disability service providers and BME service providers. This would have assisted with identifying support groups for parents and carers of disabled children, and could have yielded more South Asian parents as participants.

Flynn and Patel (2002) argue that networking with local community organisations and developmental work within local communities can assist with the identification of participants from South Asian communities. Consequently, the research time-scale should allow for networking and community development, which is often overlooked by the funders of research (ibid).

In future research with socially excluded groups such as South Asian parents and disabled children/young people, who are an invisible group in society, the research schedule will include networking and community development (Flynn and Patel, 2002).

Summary

CSR, the Social Model and adaptive theory were appropriate for researching South Asian disabled young people and their families because:

- The taken for granted assumptions about their social reality were explored.
- Their voices were sought and heard.
- Social change occurred in their lives.
- Data analysis was conducted with emergent, prior and substantive theory regarding disability and racism, which substantiated the view that disabled children/people are excluded from mainstream life because of the dominant ideology about disability and racism.

The interview, as the main method of data collection with three groups of participants, allowed the participants to express their experiences in their own words, thus grounding the data in their respective social reality. However, some learning outcomes emerged from the research practice and approach. Overall, the research practice and procedures that were used to achieve ethical practice and rigour in the research was suitable for researching the South Asian disabled children/young people and their parents. This was demonstrated by the application of the research approach to the consultation of disabled children/young people in Leicester and also to two small-scale studies that were conducted regarding BME and South Asian families with disabled children. In the next chapter, the findings from the parents' interviews are presented and analysed.

CHAPTER 4 SOUTH ASIAN PARENTS' EXPERIENCES

In this chapter, the South Asian parents' experiences are presented and analysed in the main sections stated below.

(4.1) Like other children but different

(4.2) Participation "depends on the disability"

(4.3) Service provision

(4.4) Discussion and Conclusion

Pseudonyms (as defined in the table below) are used to refer to the parents and disabled children and young people. Some of children's ages recorded in the table were calculated from birth dates provided by their parents. In other cases, parents directly supplied verbal information about their children's ages.

Table 13: Pseudonyms of parents and their disabled children/young people

Parent	Child/Young person Gender: Female (F) Male (M) Age (of child)		
Amina	Malka	F	15
Farida	Imran/Faraaz	M	15+
Maya	Ajay	M	15
Mr and Mrs Patel	Rajan	M	12
Mr and Mrs Raja	Davinder	M	8
Nadia	Ayesha	F	1
Naseem Banu	Asif	M	6
Rekha and Sunil	Rohit	M	7
Shanta	Kamini	F	14
Sharmila	Rajeev	M	7
Zaida	Jamila	F	12

4.1 Like other children but different

He does most things what normal kids [do], if you saw him you won't know that he's got this condition... (Mr Patel, parent)

A significant finding that emerged from the parents' interviews is that they described their disabled children as being like other (non-disabled) children, but their experience of parenting disabled children was different. This is because caring for disabled children included experiences of social exclusion and hardship because having a disabled member in the family affects the other family members (Fazil et al, 2002). Therefore the parents' interaction with their disabled children was informed by their experience of difference and is demonstrated by how they discussed and behaved towards their disabled children.

The parents reported that their children liked and disliked aspects of their lives that were in keeping (as children/young people) with their non-disabled peers, as illustrated by the examples in the table below:

Table 14: Disabled children/young people's likes and dislikes

Like	Dislike
• leisure activities • going out and eating out • shopping • music • television/video • computers • reading • writing • playing with toys • some enjoyed school and homework • some liked company	• sports and exercise • certain food • loud noise • other children playing with their toys • hospital

4.1.1 Experiences of Difference

...It's just a child, he's our child there [is] nothing else. Everything feels different compared to raising the other children, it just feels that he is a different child (Maya, parent)

It has made a lot of difference in my life because I [have] not had such experience (Amina, parent)

It has changed my life (Nadia, parent)

The parents felt different because of the way that they were treated (by individuals in society and by services), the changes that occurred in their lives and the feelings that they experienced as a result of their children's diagnosis. The findings pertaining to these areas are presented and analysed in the following sub-sections:

(4.1.2) Social isolation

(4.1.3) Extra caring responsibilities

(4.1.4) Feelings about having disabled children.

4.1.2 Social isolation

Sit in the house, sort of hide her you know, shouldn't go to social functions, anything (Zaida, parent)

The parents experienced social isolation in the wider society and their own (caste/jati) communities (defined and discussed below). Common to both areas were their experiences of societal response to disability and inaccessible environments, which contributed to social isolation. Zaida recalled that when her daughter (Jamila) was diagnosed, she did not go out, because she felt that they might be stared at:

Never used to go out - for 5 years used to keep her in (because) people were going to look at her (Zaida, parent)

Rekha and Sunil were stared at when they took their disabled child (Rohit) to the park and the hospital. According to Sunil:

> *At [the hospital], when we feed him people look and feel strange. They look at you and wonder what you are doing, but we usually feed [him] where people are not about because [we] feel embarrassed (Sunil, parent)*

This could be because, in general, there is a lack of disabled children's and adults' presence in society and therefore they are an invisible group in society, and draw attention and curiosity from other people. For example, some parents said that they were asked questions about their children's impairments. According to Amina:

> *When they [other people] saw her they ask that do you everything for her? Does she understand everything? Why doesn't she talk? Silly questions like that and we feel more (Amina, parent)*

Amina went on to explain:

> *You know over there [abroad], people outside who look, find this unique of how this is, because till she was five years old she wasn't sitting, she wasn't talking and her face was different (Amina, parent)*

According to Sharmila:

> *I don't feel bad as well. They're [family members and other people] that all. I look different way, they need to learn things (Sharmila, parent)*

Being "stared at", and asked questions made the parents feel that they were different from the status quo, which could be a reason why some of the parents such as Shanta felt that their children's appearance (in which impairment was hidden) was important, because it could allow them to 'fit into' the status quo and reduce their experience of 'otherness' due to non-disabled people's curiosity. However, a hidden impairment could result in a loss of services, benefits and support because the need for support is not obvious.

According to Shanta:

> *You wouldn't be able to tell that something was wrong (Shanta, parent)*

Some of the mothers in this study felt that they were the only ones with disabled children, until they took their children to school and saw other disabled children and their parents. According to Amina:

> *When I came here and took her to school to admit her, then I saw other children with disabilities. I felt some peace in my heart that other people had such children. I didn't feel that only my daughter is like that (Amina, parent)*

The response of non-disabled people towards disabled people who do go out is often of inquisitiveness and sometimes fear (due to general ignorance about disability). Non-disabled people might hesitate to offer support to disabled people and/or their carers when required. For example, Shanta found that she required help with lifting her daughter's (Kamini) wheelchair onto roadside curbs, and when she wanted to use public facilities. However, according to Shanta *"Indian"* people were reluctant to help, in contrast to the members of the indigenous population, who were generally helpful. Consequently, she sought assistance, if required, from the latter.

The parents incurred increased caring responsibility as a result of a lack of support from informal and formal sources with caring for their disabled children. Consequently, they had less time and energy to pursue social activities and their opportunities to go out were limited. For example, Nadia's child (Ayesha) required constant care and attention, including personal care, which left Nadia little time for herself:

> *Yeah, it has because since I've had her like, I can't really do nothing (Nadia, parent)*

Going out was less spontaneous for parents with disabled children, because of the planning that was required to meet their disabled children's needs, which could be time consuming and a deterrent. According Mr Patel:

> *Your life revolves round the children, they're your first priority. Whatever, you do, [you] think about would it be possible for that particular child to live in that environment or do the activity. Anything you plan to do [you] think about that first, will he or she be able to fit in…? (Mr Patel, parent)*

Unhappiness, resulting from their children's diagnosis can inhibit parents from socialising. Naseem Banu felt less happy and did not feel like going out, which resulted in isolation. The literature (Katbamna et al, 1998; Read, 2000; Mir et al, 2001; Hatton et al, 2002) suggests that parents and carers with disabled children and relatives, experience depression as a result of their children and relative's diagnosis, which is compounded by their experiences of discrimination in society and service provision.

The social isolation that the parents and their children experience could be both externally imposed by society and self-imposed by the parents and children. However, attitudinal and individual responses to disability (i.e. inquisitiveness, fear, ignorance, and abuse) can compel the parents and disabled children to impose self-isolation to shield themselves from the negative reaction of non-disabled people towards them.

4.1.2.1 Community (caste/jati and faith) groups

The parents felt that their disabled children should be included in attending celebrations (weddings), festivals, cultural and religious activities, because disabled children are part of the community and by being included they would become familiar with these. According to Farida:

> *Should take them, so they know how things are happening, because if some children have behavioural problem, their parent may not be able to cope in crowds and therefore they don't take them. But they should take them so they know where they have been to and not been to (Farida, parent)*

However, not all the parents included their disabled children in these events, because these were often organised by their community (caste/jati and faith) group. Community (caste/jati and faith) group, in this study, refers to groups, which consist of people from the same caste/jati and religious groups such as Hindu and Islam. Caste/jati is referred to in the Indian context in which *"The jati are locally defined groups within which the caste ranks are organised"* (Giddens, 1997:241).

Community (caste/jati and faith) groups are a vital source of socialising for South Asian families, and allow the parents to meet other community members and be part of their own community group. However, according to some of the parents the inclusion of their disabled children in their own community (caste/jati and faith) groups was inhibited due to inaccessible environments and societal attitudes regarding disability. For example, Shanta did not take Kamini to her community celebrations and festivals because the venues were inaccessible for wheelchair users and the space restricted. She felt unsupported by members of her community and was asked questions about Kamini's impairment. Shanta also found taking the 'buggy' in the car difficult, which resulted in her staying at home with Kamini, whilst her partner attended the functions with, or without, their other non-disabled child. According to Shanta:

> *Indian people never help or say they'll look after your baby. At wedding nobody said we will look after your baby if you want to go have your meal. It hurts (Shanta, parent)*

Farida found it difficult to push her son's (Imran/Faraaz) wheelchair and he would not allow anyone else to do this for him. Consequently, she did not take him to functions and weddings (which he liked very much) like she used to, when he was younger. Consequently the parents and their disabled children (such as Shanta and Farida) were inhibited from participating in their own communities, which could result in the disabled children being less familiar with their own festivals and celebrations, whether or not similar kinds of events in mainstream community groups would have been accessible.

Furthermore three of the parents reported that their disabled children attended Christmas parties, which were generally organised by their children's special schools and/or voluntary organisations that worked with disabled children and adults. Both of these agencies are assumed to be aware of the needs of disabled children and adults and therefore able to meet them. However, they may not necessarily be culturally competent. For example, the service providers' data (chapter 6, in this study) suggests that specialist disability services focused on disability issues and BME organisations on ethnicity, resulting in the needs arising out of both disability and racism not being met by the service providers.

The exclusion of South Asian disabled children/young people from social functions that take place in their own community group is likely to result in their isolation and invisibility. Consequently awareness of disability through the participation (visibility) of disabled children and adults in their own communities is less likely to occur, resulting in a Catch 22 situation.

The DDA Act 1995 should go towards enabling the access of disabled children and adults to a wide range of services and facilities such as mainstream community organisations and also their own community groups. However, this needs to be complemented with raising awareness about the DDA 1995 and the discrimination that South Asian disabled people experience in their own communities because of societal attitudes to disability. This might compel South Asian carers and disabled people to challenge inaccessible venues and functions.

The Joseph Rowntree Foundation recently funded four grass-roots development projects to build knowledge about how services and support could be improved to BME disabled people (Singh, 2005). However, this is unlikely to include the views of those people who do not use local and community groups and centres, but use their own community groups, such as some of the parents in this study.

This study sought the views of people (South Asian parents) to whom some services are relevant but are not necessarily accessed by them, which enabled them to present their views, which could also inform policy and practice.

Socialisation, in community (caste/jati and faith) groups, occurs at a local level and members of the group have a sense of belonging to a group identity at a micro level, where there is pressure to adhere to the particular group's 'norms'. The inclusion and exclusion of disabled children/adults in this area requires further research, to elicit views and educate communities at this micro level. This should allow representation of views from a wider group of South Asian disabled people and communities, than the usual few that participate in consultation processes, regarding the improvement of services.

4.1.2.2 Impact upon the disabled children and young people

The parents' reluctance to go out with their disabled children resulted in their children's social exclusion. Parents of disabled children often juggle between being protective towards their children and allowing them independence, and are often criticised for being overprotective of their disabled children (Cavet, 1998b; McConkey and Smyth, 2003). The parents in this study reported that their children, required supervision all the time. The parents were concerned about their children's safety and their potential vulnerability, which was compounded by the medical advice that some parents had received regarding their children's participation in mainstream activities. This contributed to the children/young people's social exclusion.

According to Mr Patel:

> *Rajan needs supervision all the time, particularly in new places. When we go somewhere such as 'seaside' we have to be careful that we don't walk too far away from him, we need to be near him (Mr Patel, parent)*

Rekha said that:

> *Someone needs to be with him all the time otherwise he may hurt himself (Rekha, parent)*

Amina ensured that Malka was not left alone at any time when she was at home because she 'might mess things up' if left unattended. Thus Malka seemed to have little time at home on her own, and spent a vast amount of time in the company of non-disabled siblings and adults.

Supervision of their disabled children/young people added to the parents' caring responsibilities and also inhibited the disabled children/young people from engaging with their peers. Both the disabled children and their peers might decline from interacting with each other because of being observed by adults or non-disabled siblings. According to Naseem Banu:

> *He doesn't play out much because someone has to look after him (Naseem Banu, parent)*

The message that is transmitted to the disabled children/young people and their non-disabled peers (by the parents' behaviour such as supervision) is that they are different because of their impairment. This can reinforce the notion that disabled children/young people's participation in mainstream activities is limited due to their impairment, rather than social barriers. Some of the disabled children in this study, according to their parents, were aware of their impairment and the difference that they experienced. As illustrated by Sharmila:

> *It [is] not really making any difference to him, except he thinks why does he have a problem? He gets upset sometimes, but he is accepting as well, that he [has] got a problem (Sharmila, parent)*

The disabled young people could internalise the view that they are different and adopt various strategies to cope with this (Watson, et al, 1999).

The following parental expressions show that some of the disabled children/young people dealt with their experiences of difference by excluding themselves from engaging with their non-disabled and disabled peers, which perpetuated their invisibility. According to Naseem Banu:

> *He doesn't keep many friends, doesn't like big crowds (Naseem Banu, parent)*

Mr Patel, said his son (Rajan) did not play outside much because he gets called names:

> *People start making fun of him so he stays in (Mr Patel, parent)*

Zaida explained that her daughter (Jamila) preferred her own company and did not mix with her other daughter's friends and other people who visited their house. Jamila also did not like to be with children and people (at school) who had the same impairment as her, and also did not like to see pictures of them. This could be because she was reminded about the difference that she experienced because of the (dominant) perception of individuals in society and services that impairment is a 'defect' and a limitation to participation in mainstream life, resulting in differential treatment and exclusion.

By being excluded the South Asian disabled children/young people in this study were likely to spend time on their own and/or in the company adults, who were familiar to them. This means that they have greater potential of being supervised and observed by adults than their non-disabled peers. Constant supervision of disabled children/young people could diminish their self-esteem about their abilities, and also their social skills and confidence to interact with their peers because they spend a lot of time in adult company. A way forward with enabling disabled young people to interact with their peers and other people in society with minimum supervision, could be McConkey and Smyth's (2003) model of 'shared-risk' in which the teenagers with their parents and professionals (as relevant), work together to explore and reduce risks.

Thus teenagers would *"have the opportunities to develop competencies to protect themselves from dangers"* (ibid:27).

Summary

To the parents in this study their disabled children were like other children (non-disabled), but their experiences involved in actually parenting disabled children were different because caring for disabled children included experiences of social exclusion and hardship. The parents and their disabled children experienced inaccessible social environments and negative attitudes towards disabled people both in their community (caste/jati and faith) groups and the wider society, which were designed for the majority – non-disabled people. Their response was self-isolation to protect themselves from curiosity, fear and possible abuse, which perpetuated the disabled children/young people's invisibility in society. The parents' ability to achieve the balance of being protective and allowing their disabled children independence to engage in mainstream activities with their peers was compounded by:

- Medical advice that inhibited their children's participation in all the activities.
- The parents' fear of their children's vulnerability to abuse.
- The parents' lack of faith in their children's abilities to look after themselves, which resulted in them spending a lot of their time in chaperoned company.

The message that was transmitted to the disabled children/young people and society is that they are different to their non-disabled peers, which resulted in self-imposed isolation by the disabled children/young people themselves, a process compounded by their parents and society.

4.1.3 Extra caring responsibilities

Can't have time to myself, can't do the housework (Nadia, parent)

All the parents experienced extra caring responsibilities because of a lack of support for parenting their disabled children.

The parents of the children with cognitive, communication and/or mobility difficulties assisted their children with personal care (such as bathing, toileting, dressing, feeding, etc.), which added to the parents' caring responsibilities, as described by Farida:

> *...Have to [do] everything for him, bathing, toilet, washing, changing everything, putting on nappy and nighty at night. Putting him to bed. Everything like what we do for a small baby, like that, except for feeding, (because) he eats (by) himself (Farida, parent)*

However, some of these children were able to bath and dress themselves, although the parents felt that they were slow and unable to perform some functions such as tying shoelaces. Thus the parents assisted them with bathing and dressing, according to Amina:

> *Dressing and changing, she does this herself, but she is very slow, takes 1 –2 hours to put clothes on, because she still doesn't know what is wrong and right side (she) puts on as they are (Amina, parent)*

Quinn argues that whilst the parents of disabled children assist their children to conduct personal care such as dressing, because it would be less stressful and time consuming *"...it robs the child of the opportunity to learn these essential skills"* (1998:94). The implication is the children's 'infantilisation' because their progress to be self-sufficient is inhibited, which is linked to attaining maturity and independence.

The children with visual impairment did not require assistance with personal care. However, according to their parents, they required supervision, which added to the parents' caring responsibilities (as discussed in the previous section).

4.1.3.1 Who are the main carers?

All the parents said that they received support with caring for their children from one or more of the following: their partners, siblings of the disabled child, family members of the extended family, friends, neighbour and other parents of a disabled child. Despite this, the main carers of the disabled children in this study were the mothers, which is consistent with other research regarding disabled children such as Beresford, 1995, Chamba et al, 1999, Hatton et al, 2002 and Read, 2000.The role of mothers as carers was reinforced by some of the fathers going to work, resulting in the mothers taking on greater caring responsibilities. Read (2000) found that some of the mothers of disabled children adopted the bulk of caring responsibilities because the roles between the mothers and fathers were divided. The fathers were often in paid employment whilst the mothers adopted domestic and caring responsibilities. The professionals who intervened in the lives of disabled children and their parents also influenced some of the mothers in taking on the main carer's role. Shanta, was informed by the social worker that she would not be able to go to work and care for her disabled child, which resulted in Shanta giving up work to look after her child:

> *Social worker said I need to think because can't do both, I left work (Shanta, parent)*

More women are now both working and caring, according to the EOC:

> *Women still often bear most of the responsibility for household work, for childcare and care of the elderly, even when they are employed (2004:1)*

Thereby women experience more stress, although in general if the caring role makes too many demands, women may be forced to give up their jobs to become full-time carers. Families with disabled children incur additional costs (Cavet, 1998b; Chamba et al, 1999) and the financial hardship that some families experience is compounded by the mothers giving up employment to care for their disabled children (Statham and Read, 1998; Barnes et al, 1999; Chamba et al, 1999). Regarding the immediate family unit, the help that the parents received from the siblings of the disabled children was varied. However, the parents recognised that these children have needs of their own and were reluctant to overload them with caring responsibilities.

4.1.3.2 Support from extended family

All the parents received support from members of their extended family. However, the support that was received by the parents varied, for example, Farida was supported by "*everyone*" in the family, whilst Shanta was supported by only one member of the extended family. Three parents (2 men and 1 woman) did not have members of their extended family living locally and/or in the UK. Some of the parents had emigrated from other countries, without members of their extended families, resulting in a lack of support from this source. Despite this, some of the parents felt that the availability of statutory support in this country was better than in the countries from which they had emigrated.

Flynn and Patel (2002) found that South Asian families preferred kinship care because of their knowledge about the families' culture, tradition, religion and language. Yet, some South Asian families do not have access to family support and kinship networks due to immigration (Ahmad, 1996), which has contributed to the break-up of family groups hence a reduction of kinship networks (Katbamna et al, 1998). The informal support that was received by the South Asian parents varied, with some parents being more supported than others.

If services providers generalise the support that is received by Farida to other South Asian parents of disabled children, it could result in an inaccurate assumption about the support that is received by South Asian parents from their extended families. Thus those parents who are not well supported could lose out on receiving support from services and remain unsupported by both informal and formal sources. Another aspect regarding support from the immediate and extended family is that mainly non-disabled people, who did not have an implicit understanding and/or experience of disability, offered support to the majority of the parents. This could compound the isolation that the parents experienced, of being on their 'own'. In this study, only Zaida said that she received support from another parent of a disabled child within her extended family, which enabled her to share common experiences of having disabled children.

4.1.3.3 Support from friends and neighbours

Three parents out of the eleven, mentioned friends as a source of support. Mr Patel found his son's (Rajan) friends supportive because they looked after Rajan when they went out. This seemed important because as a young person Rajan wanted to go out with his friends but Mr Patel was concerned about his safety and that he was "*not left on his own*". McConkey and Smyth (2003) argue that as children grow older they want to go out with their friends and it becomes difficult for parents to balance between being over-protective and encouraging independence.

Farida received support from friends in who lived in her local vicinity:

> *[Friends] help who live opposite. If I've gone out then the school van would drop him there at her house. She also looks after him. Sometimes when I'm unwell, she brings dinner (Farida, parent)*

Farida was also the only parent who said that she received support from her neighbours with looking after her son (Imran/Faraaz), which means that those families who are not supported by their neighbours miss out on support from this avenue.

According to Farida:

> *My neighbours are very nice, they sometimes when I want to go shopping or cooking they are sitting outside, they say you can leave him here. It's all right that he stays with them. They don't like it when Imran/Faraaz is not there (Farida, parent)*

4.1.3.4 How were the parents supported?

The parents were supported with specific tasks such as shopping, rather than assisting them and/or their disabled children to have a break. Thus the support was for the benefit of the parents rather than the children, although Mr Patel and Farida reported that their respective children were supported, in the following ways:

- Guiding the child and explaining the environment etc. which was done by sibling, family and friends of the parents and the child. According to Mr Patel:

  > *They look after him, they support him, guide him, [they] are aware of his problem so ...make sure he is OK (Mr Patel, parent)*

- Aunt took the disabled child out and to stay at her house for a couple of days. This was possible because the preferred gender based personal care that was required, was offered by the uncle (aunt's partner). According to Farida:

  > *Even now one of my sisters takes him to her house to stay overnight. Her husband bathes him and does everything for him (Farida, parent)*

None of the parents mentioned receiving support with personal care and household tasks, which were mainly conducted by the main carers, such as the mothers, although the fathers helped with these tasks too. Some of the mother's caring role was exacerbated when their partners experienced ill health, which resulted in them caring for their disabled children and their partners, without additional informal and formal support.

During the research Maya's husband experienced ill health, which resulted in Maya caring for him and her son (Ajay). Farida and Zaida also reported caring for a family member and their respective disabled children. During the research, Farida, experienced ill health and requested support for her son from statutory service providers for a short period of time, which was declined initially, because the service providers expected her husband to take on her responsibility. However, support was subsequently granted due to Farida's persistence. Only Maya and Shanta, received home help with their children whilst other parents such as Farida, Amina, Rekha, and Nadia also cared for children who required support with personal care. However, Amina said that she was offered home help, which she did not take up because she wanted to care for her child (Malka) herself.

To the parents, caring for their disabled children was a holistic experience, which included love and a duty to look after their children. This is reflected in the parents' reluctance to use services such as home help and short-breaks in which the quality of the care provided by other people might not match the expectations of the parents. According to Amina:

> *I didn't feel in my heart that I could leave her with anybody else and go because she [is] like that, if they could handle her and not, you know (Amina, parent)*

4.1.3.5 Short break services

Only Maya and Shanta used short-break services (respite), whilst the rest of the parents did not. Although, Rekha had used short-break services before going abroad (for a shorter period than she had wanted) and was dissatisfied with it because she was not granted a break for a longer period.

Some of the parents were reluctant to use short break services because they were concerned about their disabled children's vulnerability to abuse and they were unconvinced that the agencies providing the services were culturally competent to meet their needs.

Farida felt that although the services might claim to provide Halal food, her son (Imran/Faraaz) would be unable to tell whether it was Halal or not. Farida also considered respite in which children were sent away from home as inappropriate and preferred that the children remained part of the family and were not treated differently to other non-disabled children. According to Farida:

> *They told me about respite but my husband says no, he [son] might feel that because he is like that he's been sent away, why are they not sending normal children? They are going to feel this. He is not mischievous, that we can't look after him. It's not like that" (Farida, parent)*

Short-break services still appear unappealing to BME/South Asian families despite the recent inclusion of a wide range of services such as sitting services, home-based and family based care and short-break services (Flynn, 2002). This is evidenced by the under use of short break services by the parents in this study, which echo the findings of studies such as Flynn (2002), Flynn and Patel (2002), Mir et al (2001) and Raibee et al, 2001. These studies show that to increase the use of short-break services by BME and South Asian families, they need to:

- Provide appropriate information about short break services.
- Be flexible to meet individual needs.
- Be culturally competent.

Other aspects regarding short-break services that require further examination are:

- Contracting of services to external short break providers that include BME providers. Flynn and Patel (2002) found that there were virtually no BME providers (in the Shire County that they investigated) and that organisations from these communities expressed a desire to provide short-break services to BME disabled children and their families.
- Assessment procedures to qualify for short-break services should be appropriate to BME and South Asian children and families, and should also take into account their commitments and circumstances (Mir et al, 2001).

Summary

The parents experienced extra caring responsibilities, including supervision due to a lack of support with caring for their disabled children. However, the mothers bore the bulk of the caring responsibilities. The support that was received by the parents from their extended family was varied, with some being more supported than others. Support with domestic chores and personal care was lacking and is an area in which assistance would provide relief to the parents, particularly when caring for more than one person in the family. All the families did not use short-break services.

4.1.4 Feelings about having disabled children

> *Well, when they first told me I couldn't believe it. I mean I still wouldn't accept it. I was really shocked…(Nadia, parent)*

In recalling their feelings regarding their children's diagnosis the parents seemed to reflect the tragedy model of disability in which impairment is associated with 'defect' that could impinge on their children's ability to be self-sufficient, resulting in a dependence upon their parents for care and support. This could increase the parents' caring responsibilities. From a Social Model perspective the parent's feelings of tragedy is informed by the persuasive ideology in society that view impairment as a 'defect' and individuals with impairments as requiring care and support. Furthermore the social barriers that prevent disabled people from being self-sufficient (rather than impairment) and force them into a dependent and restricted role, are not acknowledged, which presents a conceptual barrier to viewing disability in a positive light (Sapey, 2004). French and Swain argue that perceiving disability as a tragedy can have a *"disabling"* effect on disabled people because it *"…denies their experiences of a disabling society, their enjoyment of life, and even their identity and self-awareness as disabled people" (2004:39).* The South Asian parents' view of impairment as a tragedy is also based upon how they and their children are treated by individuals in society and by service providers.

According to Mr Patel:

> *A child's a child. When you got a child you put away, you don't [think] of disability. Make your eyes open to the world, what people are really about, what the professions are about, which organisations, which staff are really there, who want to know your problems. How difficult it to get access to information, it is really difficult. If not a common problem then difficult to find out where to get help and how to get diagnosis, medicine, etc. What about other places in the world? (Mr Patel, parent)*

According to Shanta:

> *It's very difficult. God shouldn't give us disabled child. If I want to do things then I have to think of the child (Shanta, parent)*

According to Farida:

> *There is nothing good, there's only worries till his life becomes normal (Farida, parent)*

Farida added:

> *But you have to think that you've got a special child because we are more fond of them (Farida, parent)*

Sharmila explained that:

> *Disability is something nobody wants to have it, but if have it then you have to look at it [in a] different way. Not to talk about it all the time. You can't do this, you are this or that otherwise you're putting down all the time (Sharmila, parent)*

However, Zaida expressed a positive view:

> *Downs, she being a Downs, she's very loving and caring, naturally. She's independent and so natural, really nice (Zaida, parent)*

4.1.4.1 Searching for answers

The parents searched for explanations for their children's impairment and they felt that medical intervention had contributed to their children's impairment and/or made this worse. According to Amina:

> *We felt ...that how come this happened, then we found out. The doctor said it was medical (Amina, parent)*

Some parents felt that the delay in diagnosis and therefore medical intervention had worsened their children's impairment. For example, the process of diagnosis and medical intervention was quicker for the children who were diagnosed at birth or soon after, than for those children whose impairments were identified later. Intervention of services sooner can assist parents to reduce the isolation that they might experience and to access information to support their children. According to Rekha:

> *Firstly we went to the CDC [Child Development Centre] to teach him to do things and function and now he is better (Rekha, parent)*

Although the role of intervention can help parents it could also influence their interaction with their disabled children (Ferguson, 2001). For the parents, having their disabled children was their first encounter with the issue of disability. Thus they did not have prior experience and/or knowledge about disability, and were likely to agree with the professional's opinion about how the children should be assisted (Murray, 2000). Consequently, the decisions made by the professionals about the treatment and care of their disabled children might go unchallenged by the parents. Read (2000) found that some of the mothers in her study began to challenge the views of professionals, as they became comfortable and informed about their children's diagnosis, which generally occurred later rather than at the beginning of the diagnosis.

Blame

The parents explored whether they were responsible for their children's impairment and whether they could have prevented it. Thus they felt guilty and blamed themselves for their children's impairment, as illustrated by Sharmila and Zaida:

> *You do blame yourself sometimes. Maybe I have done something wrong, my pregnancy wasn't right (Sharmila, parent)*

> *Why me, sort of done something wrong, why? (Zaida, parent)*

Some of the parents also felt that the members of the family, community and wider society held them responsible, for their children's impairment. Katbamna et al (1998) found that the parental carers in their study were considered responsible for their children's disability. Thus the parental carers were selective about the information that they shared with other people regarding their children's impairment.

Religion

Some of the parents turned to religion as a means of seeking answers to their children's impairments and also to seek solace as the following expressions illustrate:

> *Why did God do this? (Shanta, parent)*

> *...Said that God gave her, so there will be some avenue (Amina, parent)*

Westcott and Cross (1996) argue that the leaders of the main religions in the world project the message that impairment is punishment for sinful behaviour. In Hinduism and Sikhism the belief of reincarnation is based upon Karma – good and bad deeds conducted by individuals in the past life. Thus parents such as Shanta wondered what deed they might have committed in the previous life to have disabled child.

In Islam, the belief is that it is the will of Allah, and because of this, parents such as Amina, place faith in God to provide solutions for their disabled children (Westcott and Cross, 1996; Katbamna et al, 2000). Irrespective of the religion, the parents in this study found religion a source of support to deal with the social exclusion due to attitudes to disability that they and their children experienced.

Parents of disabled children also experience the disability discrimination that is experienced by their children, because they are viewed by other people as contributing to the 'otherness' of their children (Katbamna et al, 1998). Members of the family, including siblings also experience discrimination due to having a disabled family member (Fazil et al, 2002). Zaida explained that the peers of her other non-disabled children asked them questions about their disabled sibling and also called her names. Subsequently, they came home and asked Zaida why Jamila was disabled, which she found difficult to explain. Shanta, addressed her son's questions about Kamini's disability by taking him to her nursery to familiarise him with disabled children, which she hoped would enable him to deal with being bullied about having a disabled sibling. Topliss (1979) argues that:

> *Where the disabled member of the family is a child, not only is the parent/child relationship likely to be affected, which most people can readily understand, but also the relationship between the spouses and between the siblings (1979:136)*

By exploring and locating the responsibility for their children's impairment to external sources such as medical intervention (but not social barriers), the parents seek to reduce their feelings of guilt and responsibility. Depending upon the diagnosis, medical explanations can help the parents to inform their disabled children, other people in the community and society that they are not responsible for the impairment and that the family lineage (genetically) is not 'faulty'. This can help to deflect responsibility for the impairment from the parents but it does not reduce the effect of individualising impairment, upon the children, because it is the impairment which is considered a limitation on the

individual's ability to 'fit into' the status quo, rather than the social barriers that inhibit inclusion. Because they were focusing so much on explanations regarding impairments, the parents therefore did not seem to explore social aspects (and social barriers) such as the inaccessible environments and attitudes of other people that prevent disabled people's inclusion in mainstream life. Thus knowledge about impairment could help the parents to respond to their children's queries (about impairments), but it could not assist them with explaining the social barriers that contributed to their children's experience of difference and social exclusion. For example, some of the disabled children in this study were aware that they had impairments and/or were treated differently to their non-disabled siblings and peers. They asked their parents why they had impairment. According to Mr Patel, his son (Rajan) *"asks why me?"* Mr Patel's response to this was that if they could do something to prevent and/or cure his impairment, they would have done so. Some of the parents in this study actively sought additional information and possibilities of a cure and/or improvement regarding their children's impairment from a wider range of sources.

4.1.4.2 Improvement - hope

The parents hoped that their children's impairments would get better in the future, and that they might be able to participate in daily life like non-disabled children and adults. Mr and Mrs Patel sought a second opinion regarding their son's (Rajan) diagnosis:

> *We don't give [up] hope and have tried everything and are still trying…treatment [is] not available. [In] London they said that treatment not available now, but give it 10-15 years there may be something available for him, and it can't be far off, something will be there (Mr and Mrs Patel, parents)*

Shanta expressed hope for her daughter (Kamini):

> *I hope she walks. I asked the doctor if she will walk as she has strong legs. The doctor said we can't say 50/50 chance, but I want them to tell me although I know it's difficult for them to say because it may give hope or disappoint me (Shanta, parent)*

The parents compared their children's abilities to those of their non-disabled peers, thus improvement of their children's impairment was measured against what they could not do at present. For example, the parents with children with mobility difficulties hoped that their children would walk in the future. This could be because most of the children were young and therefore might have the opportunity to access advanced medical treatments, which might improve their children's abilities. It could also be because professionals (such as psychologists and Health Visitors) are obsessed with measuring all aspects of a child's development, which therefore creates the standard of what is, and what is not 'normal' growth and development at different ages (Priestley, 2003). This is concerning because the message that is transmitted to the disabled children by services and the parents is that there is something wrong with them which needs to be corrected, without which they would be incomplete. The children could internalise the view that they have to be like their non-disabled peers to participate in mainstream life. Thus they might think it is their impairment that is preventing them from participation rather than the structures of society (French and Swain, 2001). Consequently, the children could adopt their parents' quest of searching and hoping that their impairment improves, as indicated by Rajan (disabled young person) in chapter 5. Thus both the children/young people and their parents could consider a medical solution to their situation to be more effective, rather than questioning the way society prevents their participation and social inclusion.

Summary

The attitudes of individuals in society and services towards disabled people contributed to the parents' distress at their children's diagnosis. The children are subjected to intervention from services, which project impairment as a tragedy, and also view it as a 'defect' by using the medical model to treat and/or rehabilitate the children to be like their non-disabled peers. The parents explored factors such as medical interventions and their own role that might have contributed to their children's impairments, which could help to reduce their feelings of guilt. By developing their knowledge the parents were able to explain the source of the impairments to their disabled children, but not the social exclusion they experienced due to the social barriers preventing their participation in mainstream life and activities. The message that is transmitted by the attitudes of individuals in society and the professionals is that it is undesirable to be disabled and thus parents hope for their children's impairment to improve so that they are able to participate in mainstream life like their non-disabled peers.

4.2 Participation – "depends on the disability"

An important finding that emerged from the data is that the parents' perceived that the participation of disabled children/young people in mainstream activities and life (such as those listed in question 12, appendix 9b) depended upon their impairment. However, the parents' views were mixed regarding the participation of disabled people in mainstream activities and life, and also contradictory. Because whilst they thought that disabled people should be included in mainstream activities, they also said that participation depended on the *"disability"* (the parents defined disability to mean impairment – functional limitation as the quotes below illustrate). Some of the parents' responses reflected their experiences, for example regarding education the parents whose children were in special education stated that:

Depend on the disability. If they are very physically like that then they should not put them in mainstream school, they should be in special school. If they have learning difficulties or [...] physically disabled (Amina, parent)

Depends on disability isn't it? Some have to go to special because they can't cope with the mainstream. If they are mental is OK then they can cope but if some...disability... like Jamila, I think she's in between... She can't cope with mainstream. Is Ok she can't go to the severe learning disability ... as well... (Zaida, parent)

Special school, isn't it? Because in the mainstream school, they can't communicate and children bully them, those children who are 'normal' (Farida, parent)

However, according to Mr Patel, whose son attends mainstream education:

As long as possible they should be in mainstream schools, from personal experience. If the school can take the child they should be mainstream (Mr Patel, parent)

Mixed views were also expressed regarding participation in activities such as shopping, leisure, training and employment (examples relating to each of these areas are illustrated):

I'm sure they can. It depends on what kind of disability we are talking about at the moment. Mind you, we have lots of facilities....can get lots of help nowadays if you know where to go anyway. I've noticed that at Rajeev's school [there are] quite a few children wearing hearing aids. So there are quite a few children who ...are in mainstream school (Sharmila, parent)

On their own/with other people. If they are able then they can shop on their own to a certain extent. For physically 'handicapped' then it's difficult for them (Mr Patel, parent)

Go with other people. Older people with motorised wheelchair go on their own. Seen on T.V. people without arms and hands or legs do things for themselves (Naseem Banu, parent)

On their own they won't be able to go because they won't understand so someone needs to be with them because everyone has different disabilities (Amina, parent)

Shopping with other people not on their own, what if somebody does something to them (Shanta, parent)

As regards to leisure activities Mr Patel felt that impairment should not restrict participation but that other individuals should be informed about the individual's disability:

...Shouldn't hamper anything, as long as people around them are aware of the situation. This need to be outlined before they take part (Mr Patel, parent)

Some of parents also felt that disabled people should participate in mainstream leisure activities:

Yes, I have seen [disabled people] play hockey and basket ball in wheelchair (Shanta, parent)

They could go – yes but depends. They can't be left unattended, they might feel ignored. See a few people with wheelchairs at weddings...got somebody to look after them (Naseem Banu, parent)

As regards to training and employment, the parents felt that disabled people should be provided with access to these areas, but this too was subject to people's specific impairments:

I'm sure there should have lots of facility for that [training]. They should know how to train disabled people (Sharmila, parent)

Anything that meets their potential they should be allowed to do. Work, training, anything which they are capable of they should do it. Depends on type of disability (Mr Patel, parent)

They [disabled people] should be taught and trained, depending upon disability and ability. I see programmes and have seen them working (Shanta, parent)

However, some of the parents' views regarding training and employment did not correspond with their aspirations regarding their children's future. For example, only two parents (Sharmila and Mr Patel) expressed an aspiration for their children's future, although Zaida said that her daughter (Jamila) wanted to work in a leading supermarket.

According to Sharmila, her son (Rajeev) wanted to be a pilot, which she supported:

> *He can be a pilot, there's nothing wrong to be a pilot, specially [as his] vision [is] not bad (Sharmila, parent)*

Mr Patel, explained that his son (Rajan):

> *...Is very clever and wants to go to University. He has begun to accept his visual disability now and said that he can teach Braille to other children, he is learning Braille and (is) good (Mr Patel, parent)*

Zaida said her daughter (Jamila) wanted to work in a given supermarket:

> *Yeah, it's good I think because Jamila is saying I'm going to work in [supermarket]. I don't know why she's got this thing about [supermarket], whenever we go to [supermarket] says is going to work [in supermarket] (Zaida, parent)*

Three parents (Naseem Banu, and Rekha) thought their children were young and had not yet considered their future. Maya and Shanta, explained that their respective children's future would be discussed with the services that intervene in their lives such as education. According to Maya:

> *They will tell us whether to send him to school further or send him to day centre (Maya, parent)*

Farida was confident that her family would care for her child when she was unable to, which is a contrast to the other parents who expressed concern about their children's care in the future.

> *I haven't thought [about] it yet because I am well now so I will do for it, but feel that my family will look after him if anything happens (Farida, parent)*

With regard to whether disabled people could get married and have children, two parents said that disabled people could get married, three said that they could but it would depend upon their "*disability*" and two felt that their disabled children would not be able to understand and maintain a marital relationship. According to Sharmila and Zaida:

> *Oh Ya! If they can look after themselves. I have seen people with Down syndrome do get married (Sharmila, parent)*

> *Oh! I'd like that. She's aware, yeah, she's aware (Zaida, parent)*

However, some of the parents assumed that disabled people would get married to non-disabled people (disabled men married to non-disabled women were generally referred to by the parents), who would have the responsibility to maintain the marital relationship, care for the disabled person, and any children that might result out of the relationship. According to Farida:

> *I'll tell you from my son's [experience], if I got my son married, his wife will be normal and their children will feel that their father is disabled, they will feel this, won't they? (Farida, parent)*

The perception, of some of the parents in this study, seemed to be that disabled people should be able to comprehend and be competent to engage in and maintain marital relationships. According to Maya:

> *No, I don't think he'll understand in this area?(Maya, parent)*

However, she went on to explain:

> *First we have to make them understand what it means to have a relationship with this person and how to talk to this person, if they have a relationship. So first this needs to be understood (Maya, parent)*

Some of the parents perceived their children as dependent because they required looking after and thus were considered unable to support a spouse and children. Consequently, some of the parents seemed to have decided that their children would not have a marital relationship and have children. Therefore they risked denying their children experiences regarding love, affection, companionship, sex and parenthood that their non-disabled peers have the choice to experience (Jurkowski and Amado, 1993).

As regards to disabled people and parenthood some of the parents said that this too depended upon "*disability*" and their ability to care for their children. Some parents hinted at genealogy in that the parenthood of disabled people might or might not result in disabled children. According to Sharmila:

> *I'm not sure about children, it depends. Mind you, I have seen disabled children get married. The children doesn't have any problems. It doesn't really mean if you're disabled so the person is going to have children who will be disabled at the end of the day. It depends on the individual – can't comment on that (Sharmila, parent).*

Shanta said:

> *No, not if they can't look after themselves (Shanta, parent)*

Amina explained that:

> *I have…got no idea, because there is someone, not in our chaste, but there is someone who is an Asian boy [disabled] who has got married and has children. Out of these, three have gone on him, so it's hard. For the wife, it's hard, looking after the husband and looking after the children. So, if there is disability in the genes then it carries on. According to me they shouldn't whether it's a boy or girl (Amina, parent)*

Zaida was more optimistic:

> *It will be nice. I don't know if they can cope, we always think if they can cope. We can't cope ourselves. I haven't [seen] anybody disabled getting married have I? I don't think so. I have heard of somebody blind getting married but I have not seen one getting married (Zaida, parent)*

It could be because some of the parents viewed their disabled children as being unable to comprehend the concept of marital relationships and also doubted their children's competence regarding parenting, that they did not discuss this issue with their disabled children. Jurkowski and Amado (1993) argue that carers and professionals avoid discussing the issue of sex and sexuality with disabled young people and thus they are insufficiently informed to deal with their sexual feelings, relationships and the possibly abusive behaviour of other people. Consequently, parents and carers ensure that their disabled teenagers are in supervised company, usually with adults that they trust.
This restricts the opportunities that their disabled young people have to meet with their peers, develop sexual relationships and engage in sexual activities (Fairbairn et al, 1995).

> *The main avenues available to disabled young people to raise their awareness about sexuality, sex and relationships in order to make informed choices are their peers, sex education at schools and television (Jurkowski and Amado, 1993; Fairbairn et al, 1995).*

Sex education also needs to be appropriate to BME and South Asian people's experiences, which is more than just making the material representative. It is about understanding these issues within the context of their lives (McCarthy, 1999). As regards to exchange of information via peers, this could only be effective if the peers of disabled young people have access to information about sex and sexuality. For those disabled young people (such as Jamila, Malka, Imran/Faraaz and Ajay) who spent their time with their disabled peers in activities supervised by adults, their access to information could be restricted. The consultation conducted with disabled children, young people and young adults, for the Disabled Children's Project, found that disabled young people who had left school (mainly special schools/colleges) lacked information regarding sex, sexuality and relationships. The disabled young people felt that youth sessions held within their respective schools/colleges were run by teachers, which made it difficult to discuss such issues openly. Some of the disabled young people were informed about issues regarding sex by their parent(s) and/or non-disabled siblings (Patel, 2004).

In general teenagers and/or parents are reluctant to discuss sexuality and sex with each other due to the difference in their age and status. This applies to disabled teenagers, including those from some South Asian communities in which discussion of sexuality and sex, openly, within families is considered inappropriate. Thus parents require advice, information and support about ways their disabled teenagers could access information about sex and sexuality and also so that the parents could support their children in this matter if required.

The parent's views about their children's participation in mainstream life and activities such as leisure, marriage, training and employment seemed to be rooted in their perception about comprehension and competence and reflected the individual/tragedy model of disability. However, Sharmila seemed to have some awareness of social aspects that exclude disabled people in mainstream activities and life:

It could [be] family saying that you can't do this and you can't do that. It all depends on family isn't it? I've got my aunty. She's disabled, she's suffering from X so my uncle said you can't have a wheelchair that you can run yourself. Anything can happen to you at any time, but this is scaring isn't it? At the end of the day, I think she should be allowed to do what wants to do. Mind you, give her advice but she should have at least [an] opportunity (Sharmila, parent)

Summary

The parents' view about participation of disabled people (including their disabled children) in mainstream activities and life was that this depended upon the individuals' impairment rather than whether mainstream activities and life were accessible to disabled people. This was despite the fact that some of the parents had seen disabled people participating in activities such as sports, training and employment on Television. Some of the parents had also seen and/or heard about disabled people getting married and having children, which indicated that disabled people could participate in such aspects, although some of the parents doubted their disabled children's ability to comprehend with concepts such as marriage and parenthood. Therefore they felt that their disabled children might not engage in such aspects. The parents' perception of participation in mainstream life which depended on "*disability*" – the individual's ability to cope and participate in mainstream life was influenced by the persuasive view in society that disabled people are incapable of being self-sufficient and that they require care and support. This view is based upon viewing impairment as a 'defect' and thus as preventing the disabled person from participating in mainstream life rather than social barriers that prevent their participation, and thus it presents a conceptual barrier to the parents to view disability positively.

4.3 Service provision

...There's so many people coming and going (Nadia, parent)

A range of services (statutory and voluntary) intervened in the lives of the disabled children and their families. The findings pertaining to service provision are presented and analysed in the following sub-sections:

(4.3.1) Experiences of Statutory Services (Health, Social Services and Education)

(4.3.2) Voluntary and Community Services

(4.3.3) Support groups

(4.3.4) Religious services

(4.3.5) Information

4.3.1 Experiences of Statutory Services (Health, Social Services and Education)

The parents and/or their children received services from one or more of the statutory services listed in the table below. The intervention from the services occurred at any time in the lives of the children, and as they became known to services. Thus some services were involved as soon as the children were diagnosed and some later. Some of the services were provided continuously as the children grew older whilst some tapered off to little or no involvement as their needs were perceived by the services to have changed.

Table 15: Statutory Services that intervened

Statutory Service provider	Services and/or professional
Health	Hospital Health Visitor Specialist Health Visitor Dietician Nurse Specialist Nurse Doctor Physio OT
Social Service	Registration Social worker Adaptations Home help/care Benefits Respite care
Education	Peri-teachers Portage Nursery Teacher Ancillary Transport

4.3.1.1 Health Services

Medical diagnosis of impairment is an important factor in the children and their parents' lives because this can lead to intervention from medical, specialist and support services. Information about the diagnosis and prognosis is vital for the parents and their children to manage the impairment and to access specialist and support services.

The parents were given verbal information about their children's diagnosis, and most were given a report at the time of diagnosis. Some of the parents were given detailed explanations about their children's impairment. However, Mr Patel felt that too much information was given at a distressing time, which made absorbing it all overwhelming. Mr Patel explained that the medical reports that were given were long and contained medical terms, which the parents (lay people) are unlikely to understand.

Despite this parents of disabled children are expected to process complex information about their children's diagnosis and assist their children often without help from medically trained staff (Cavet, 1998b).

Some of the parents were not given information about the treatment and/or the possible consequences of the treatment, as expressed by Mr Patel:

> *Hospital did not explain what tests they were doing, the procedure for these and the consequences. They said they were going to do this, but gave no further explanation (Mr Patel, parent)*

Thus the parents did not have a full picture about the likely prognosis of the treatment for improving their children's impairment and thus were unable to decide (with their children) whether the treatment was essential before agreeing to it. If the treatment did not work or worsened the condition, as was the case for some of the children, it could dash the parents' hopes of their children's improvement and increase their desire to search for improvement in their children's impairment.

The parents also reported a lack of information regarding stability of the impairment in the future and were therefore unable to plan for their children's future care (discussed in section 4.3.5.4).

Differential treatment

Three of the parents felt that they had been treated differently because of their ethnicity. Mr Hilal (Naseem Banu's husband) felt that his son's (Asif) diagnosis took longer because they were *"coloured"*. Naseem Banu commented that they were unsupported "*because of (being) Asian/coloured doesn't want to help*".

Mr Patel said that:

> *They think we don't understand even if we speak English, because we are Asian.*

Whilst not all the parents reported experiences of racism, negative experiences were reported which suggests the presence of institutional racism in services. Although, most of the parents were happy with the doctor/consultant at the hospital, some felt that an Asian doctor might have had an implicit understanding of their culture and tradition, and might have been able to communicate in their language(s). According to Mr Patel:

> *Asian doctor would have made a difference, because my wife doesn't speak English, she could have been more forthcoming in asking questions…. (Mr Patel, parent)*

Some of the medical professionals' attitude about disability reflected the medical model of disability, and was distressing for some of the parents. Amina recalled an upsetting encounter with a GP:

> *One doctor [Indian] said that you'll have to do everything for your daughter yourself, she will remain the same when she grows older, she will not be able to anything herself (Amina, parent)*

However, positive experiences were also reported. The parents with children with cognitive, communication and mobility difficulties found that the Health Visitor was a source of support with information and access to services, as expressed by Farida:

> *Whatever we tell the health visitor, they organise it all. All the information is given. Now I have asked about bedwetting, [and] she sent me information of places to contact. If we have a form to fill in, then she would do it if we ask (Farida, parent)*

The anxiety that the parents' experienced seemed to be worsened rather than lessened by their interaction with some of the health service professionals. Health professionals play an important part in diagnosis, confirmation and thus labelling of a child's impairment. Thus they have a powerful role in influencing the children's perception about themselves and the parents' perception about the children. The model that is projected by health professionals is that of the medical model - that there is something wrong with the child, which requires

correction and results in the child and parent entering the orbit of health, specialist and support services (Twigg and Atkin, 1994).

The parents generally agree with advice and treatment that might or might not work, because of their lack of knowledge about the impairment. In this study, some of the parents reported that their children's impairment did not improve due to treatment, which left them and their children feeling deflated because their expectations of the impairment improving were not met.

4.3.1.2 Social services/social worker

Some of the parents received intervention from social services such as the registration of their children on the visual impairment register, adaptations to their homes and assistance from a social worker. However, access to services was not easy. Mr Patel had to 'pester' social services to register his son (Rajan) on the visual impairment register. Rekha and Sunil opted to move to a specially adapted council house for which they are still waiting and in the meantime they were provided with adaptations for their son (Rohit). Naseem Banu also wanted adaptations to her home so that her son (Asif) could move about unescorted. Asif depended upon his parents and non-disabled siblings to accompany him up the stairs or for them to fetch him things rather than go by himself. However, by the second interview, Naseem Banu had contact from a social worker and was going to be provided with adaptations to assist Asif's movement within the house.

Five out of the eleven parents had received intervention from a social worker at some point in their children's lives. These were parents of children with cognitive, communication and mobility difficulties, whereas the majority of the parents with visual impairment children did not have a social worker, one parent wanted a social worker. However, one parent was unaware of social services/social worker intervention, which resulted in loss of possible support:

> *I don't know about social worker, everybody said why don't you have…a social worker? And I say, I don't know. Maybe I've not needed one or something, I don't know (Zaida, parent).*

According to the parents, the social worker intervention was inconsistent and short term. Contact by the social worker was infrequent and intervention occurred when the children were young but was withdrawn, as they grew older. Yet the need for support remained and/or increased as the children got older, according to Maya:

> *Before social worker used to come, then used to give all the information. Now they don't have staff, if someone goes there and fights at…their main office then they sometimes give. Now I'll have to go and do that because now his age is such that at 19, then need social workers for this (Maya, parent)*

Parents, such as Maya were not passive but active in mediating with services for their children's care. Middleton (1999) argues that social worker intervention is based upon meeting narrow assessment criteria and their focus is upon child protection. Thus parents and children who require support but are not at risk are sidelined. Although disabled children are an 'at risk category' they do not automatically receive intervention from a social worker. Social worker intervention is only offered to disabled children (and their carers) if it is identified as a need and/or intervention including information is requested from the parents. This means that not all disabled children (and their parents) receive intervention from a social worker, as evidenced in this study.

The parents who had social worker intervention found it useful because they were given information and advice regarding a range of issues, including being listened to, as expressed by Nadia:

> *I can talk to her [about] family problems, marriage problems, anything. I did, I used to talk a lot. It did help a lot, she gave me advice (Nadia, parent)*

Quinn argues (1998) that the role of social workers involves assessing the information and services that might be helpful, and supporting the family to understand the child's impairment. However, this can only be supportive if the social worker intervention is consistent and communication is possible between the parents, the children and the social worker. For example, Rekha said that her previous social worker spoke the same South Asian language as her, but that social worker has been replaced by one who does not and thus she experienced difficulty with communicating with her 'new' social worker.

Parents of disabled children, experience distress and have extra caring responsibilities, and thus require assistance from informal and formal sources to boost their resources to care for their disabled children.

4.3.1.3 Education services

One child was pre-school, four attended mainstream schools and/or colleges and six attended special schools and/or colleges. Some of the parents reported a lack of communication between their children's school and/or college and themselves. The parents of the disabled children who attended mainstream education said that the peripatetic-teachers did not inform them about the visits that took place at their children's school. The parents were only informed when a problem was identified and in general the children informed their parents about the visits. According to a representative of a specialist education service (interviewed in this study) home visits end once the children attend school because it becomes the school's responsibility to meet the needs of the children rather than that of the specialist services. Consequently, the parents are excluded from intervention in which they were previously involved and the focus is upon the parents to ensure contact with the professionals and the school about their children's progress.

Farida, whose son attended a special school was not informed about her son's (Imran/Faraaz) attendance at a youth club:

> *From school they take him to some youth club on ... afternoon, but I don't know where. This is in the diary, it is written that in the morning went to PE and afternoon went to youth club (Farida, parent)*

Despite this, the parents whose children attended the special schools said that their children's schools informed them about aspects concerning education, school and their children's progress.

The parents of the children who attended mainstream education reported that their children's visiting teachers were the main source of information regarding the services that they offer. However, these parents also felt that not all the information about the service was given, rather the information conveyed was according to the professional's view about the services that the parents were entitled to. Thus they were unable to assess whether they had received all the services that they were entitled to and required.

Some of the parents reported a lack of support and understanding from the schools and teachers, regarding their children's impairment. In the special school that Maya's son (Ajay) attended, volunteers supported him when changing for swimming sessions. However, when volunteers were unavailable he missed out on the swimming sessions and the school did not appear to make alternative arrangements for such occurrences. Maya reported that Ajay did not receive music lessons, which he enjoys.

Sharmila, whose son (Rajeev) attended a mainstream school, reported that sometimes the teachers did not make resources available in the appropriate format. Whilst, Mr Patel said that the teachers did not understand his son's (Rajan) impairment:

> *...He does get some teachers who think he's trying to put something off to later on or not do his work, but it's just that they don't understand his problem (Mr Patel, parent)*

The lack of support and teachers' understanding of the children's impairment can be detrimental to the children's progress in education and can result in them lagging behind their peers. This was a concern to the parents because they wanted their children to access the same education opportunities as their non-disabled peers and therefore be equipped to engage in employment and other mainstream activities. According to Sharmila:

> *You get worried that your child doesn't [get] behind compared to the other kids and things (Sharmila, parent)*

The majority of the teachers both in special and mainstream schools are non-disabled adults and thus do not have experience of disability and so are unable to offer empathy to their disabled students. In the mainstream schools, there are often few disabled children, which results in their isolation. Parents such as Sharmila, recognised the pressure that teachers in mainstream schools experienced to meet the needs of few disabled children and also the isolation that these children experienced. However, parents should not have to accept the lack of support that is provided to their children, they should be reassured that their children will be supported to have the same educational opportunities that other children have. This includes an expectation that the children do not experience discrimination due to gender and ethnicity because of a concentration on disability. For example, in Vernon's study (1996) disabled BME women's experiences of education included racism due to a lack of understanding of their cultural needs (and traditional/religious beliefs). Some of the women experienced bullying from their peers because their diet and dress (traditional) differed to that of their (indigenous) peers. The career advice received by some of the women was also influenced by stereotypical views of South Asian women – that they would get married and have children and therefore there was less encouragement for these women to achieve their academic potential. In terms of the Special Educational Needs (SEN) Statement, it details the needs of the individuals to assist with education and does not include aspects related to sexism and racism that can also contribute to 'poor' results in education.

There is also *"an over representation of BME children in special or segregated education provision – this is despite most impairments having no direct causality to ethnicity or socio-economic status" (Broomfield, 2004:50)*. This raises questions about the training and support opportunities that are available (or not) to the teachers in mainstream and special schools to explore and address issues that could lead to the social exclusion of pupils due to ethnicity, gender, disability, sexuality, religion and class.

Despite the above, the majority of the parents were satisfied with their children's schools, colleges and teachers. The parents whose children were in special education, were happy that their disabled children were taught social and life skills, although they were also critical that these were Eurocentric. Quinn (1998) argues that disabled children must learn the social conventions of the majority if they are to be part of society. This view appeared to be supported by the parents who were satisfied that their disabled children were learning social and life skills at school. Several factors can contribute to this:

- The parents' awareness that their disabled children were not being equipped with employable skills, by their special schools. Instead they were being socialised to be managed in day centres and to be cared for, where social and life skills would assist them. This might suit the parents because they have little confidence in their children's abilities to engage in training programmes and employment. Special education is generally undervalued and employers view special education and attendance at special and/or segregated courses unfavourably (Middleton, 1999). This leaves disabled children/young people who continue to be educated in special and segregated education in an undesirable position – that of being less employable and unable to contribute to the economy and their social life.
- The parents were aware of the difficulty disabled people generally experience in securing and retaining employment, which is evidenced by the lack of disabled people in employment. Disabled people, in general, experience greater levels of under-employment than their non-disabled peers do (Middleton, 1999; Barnes et al, 1999).

When they are employed, this is in low paid and low status jobs and in general disabled people earn less than their non-disabled colleagues (Barnes et al, 1999).

- The parents might prefer that their disabled children/teenagers be in safer programmes and environments such as special colleges and day centres, in which trained staff teach and/or look after them. Thus the parents' fear of their children experiencing disability discrimination and abuse in the wider society (mainstream colleges, programmes, employment) is reduced. Although there is still a potential for abuse to occur in special programmes and care (Morris, 1995, 1998a).

However, the parents of children with visual impairment (and not cognitive and communication difficulties) considered education important to attain employment and a rewarding life style in which the disabled children/young people could look after themselves in the future. This could be because these parents felt that their visually impaired children did not have cognitive and communication difficulties (to inhibit their potential) and therefore they would be able to achieve their potential with support with their visual impairment. For the children with cognitive and communication difficulties this is considered as inhibiting them to achieve their potential to look after themselves and to compete cognitively (intellectually) with their non-disabled peers (which those with visual impairment would be able to do). According to Farida:

> *If they are physically disabled then they can look after themselves, but it they are mentally or both physically and mentally, if their minds aren't working then how are they going to be independent? They themselves don't know what they are [doing] (Farida, parent)*

There appears to be a hierarchy in how specific impairments are considered (by the parents, professionals, individuals in society) as determining the ability of disabled individuals to achieve their potential both academically and economically to be independent and care for themselves.

Goble (2004) argues that some people with intellectual impairments experience greater difficulties in *"attaining and maintaining independence"* because their ability to be independent is related to prevailing notions of the mind/brain which is seen as central to enabling self independence in Western culture. According to Goble:

> *To experience impairment of the mind/brain then is, in this culture at least, to be seen to lose all, or critical part of the self, and the autonomy and independence that goes with it (2004:45)*

People with intellectual impairments then are less likely to be encouraged (than other disabled and non-disabled peers) to attain academic qualifications because they are 'already' viewed as incapable to attain independence through employment and economic activity. This could be why the parents of the children with cognitive and communication difficulties did not have career inspirations for their children's future.

4.3.2 Voluntary and community services

The parents used one or more of the following national, regional and local charities: Royal National Institute for the Blind (RNIB), Mencap, Scope, Family Fund, and British Red Cross. The local voluntary and community organisations that were used include those that provide services for carers in general and for carers of South Asian background. The parents also referred to community (caste/jati) groups (discussed in section 4.1.2.1).

The parents were provided with a range of services, which included information and support services. It was noticeable that the voluntary services and groups that were used by the parents were those that were geared to meet the needs of parents and carers of disabled children and adults. There was a general absence of use of mainstream services, including community centres and groups (used by non-disabled children and adults), which should also be accessible to all disabled children and adults, and their carers.

For example, Farida found that some of the activities that were organised in her local area by mainstream services took place in the evenings, which she found inaccessible because she looked after her son (Imran/Faraaz).
Farida felt that she could not ask someone to look after Imran/Faraaz on a regular basis, whilst she participated in activities. A lack of awareness about the caring responsibilities of parents and carers of disabled children/young people can exclude them from participating in mainstream activities that are provided by statutory agencies, and force them to use those that are specially organised for them and their children, by voluntary organisations.

Traditional voluntary organisations such as national charities (RNIB, Scope, Mencap) have philanthropic roots in the Victorian era and emerged to provide support services to families and individuals considered destitute (Middleton, 1999). Gaps in statutory services were filled by voluntary and charity groups and their roles in providing services increased as statutory services began to roll back the welfare state, by contracting services to voluntary organisations (Middleton, 1999). However, BME communities have under used established voluntary organisations, which in recent years have attempted to improve their services to encourage use by these communities (Ahmad et al, 1998). The service providers' data (chapter 6) suggests that there was an under use of specialist disability services by BME and South Asian service users, although some statutory services said that this was not an issue for them.

Voluntary groups within the BME communities have also formed and some are funded to provide services to these communities. Voluntary organisations of BME and South Asian disabled people, such as Association of Blind Asians (in London and Leeds) have also developed to address the needs of this group (Priestley, 1995; ABA, 1996; Atkin, 1996; Drake, 1999).

4.3.3 Support groups

The parents were informed about support groups by a range of professionals who intervened in their lives. Five parents (all mothers) of children with cognitive, communication and mobility difficulties attended support groups, which were organised by statutory, voluntary and community organisations. These parents found that support groups provided them opportunities to:

- Get information and ideas.
- Reduce isolation by meeting other parents, which enabled them to become stronger and more confident.
- Participate in courses.
- Become committee members and representatives of the views of South Asian carers.
- Use a wide range of toys, which their children liked to assist with their development.

However, the parents with visually impaired children did not attend support groups, although one had wished to meet with other parents to exchange information. Another parent with a visually impairment child who had not attended support groups was at the time of the second interview thinking of attending this. Not all the parents of children with visual impairment wanted to attend a support group such as Mr Patel. Sharmila was unable to attend support groups that met during the day because she worked during the day. Transport was an issue for parents such as Shanta. Therefore whilst support groups are beneficial to those parents who attend these they may not be accessible to other parents who are employed, do not have transport and require support, but not in a support group setting. Some of these issues also apply to peer support groups for BME and South Asian disabled young people. Sharmila expressed a need for a peer group for her son (Rajeev) who she felt could benefit from other young people in a similar situation to him and this help to reduce the isolation that he experienced at his mainstream school (South Asian disabled young people's experiences as discussed in chapter 5).

4.3.4 Religious services

Six of the parents reported that they took their disabled children to religious places with them, or that their children attended religious schools and/or classes. Naseem Banu's son (Asif) went to Madrasa (religious school), Sharmila's son (Rajeev) went to spiritual classes and Shanta took her daughter (Kamini) to temples because volunteers were available to support her.

Maya did not take her son (Ajay) as she used to because his behaviour was difficult to manage. Amina did not take her daughter (Malka) to pray because she felt that she might not understand the concept of praying and might disrupt the prayers.

Zaida and Amina reported that the religious places that were attended by their non-disabled children were inaccessible to their disabled children and were also unwilling to meet their needs. They also refused the parents' offer of support with teaching their disabled children. Consequently, the parents felt that whilst the statutory education services were meeting their children's needs through special provision, some religious organisations within their communities were not doing the same to meet their disabled children's religious education. According to Zaida:

> *You know Jamila goes to special school right…but us in our community they don't make special provision for special needs children, they only got for the ordinary mainstream. So like Jamila she can't go the Mosque, she just stays at home at the afternoon time (Zaida, parent).*

Thus their disabled children were unable to participate in religious education conducted in their faith communities, in contrast to their non-disabled children, and therefore were treated differently. Amina explained that there was a lack of support from other parents of disabled children to form a collective voice to challenge the religious organisation's lack of support to their disabled children's access to religious education:

> *They [parents of disabled children] are not coming together so there are only 2-3 of us left, there more of the others, but they didn't fight. We tried but they [religious organisation] are not going to listen to 2-3 people, you need big people for this don't you (Amina, parent)*

A lack of access (therefore exclusion) from religious activities means that disabled children, particularly those with cognitive, communication and mobility difficulties are further made invisible in areas where their non-disabled siblings and peers congregate.

4.3.5 Information

A major theme that emerged was the parents' 'worry' about their children's impairment and their future care. The factors that contributed to their anxiety are the lack of information about their children's impairment and service provision. This is linked to the transition of the children to adulthood and includes their future participation in mainstream life and care.

4.3.5.1 Information about the impairment

The parents did not know whether their children's impairment might improve or worsen in the future, and thus were unable to plan for their future care. The parents expressed a need for information regarding their children's impairment in the future and wanted to be kept informed about medical advancement as it occurred so that their children could benefit from these. According to Mr Patel:

> *We would like information – the doctors to keep us informed of any new ideas that would help or any new innovations, we have no feedback (Mr Patel, parent)*

Amina too expressed a desire for the following information:

> *How is her health going to improve or is her medical going to continue or what? She has improved in this time, so I think if she can improve further, then it's good. If there [is] some information about that or what solution might there be in the future like how they research about heart cancer. They must be doing research about disability? (Amina, parent)*

The parents, particularly those with children with cognitive and communication difficulties, reported a concern about their children's transition through adolescence to adulthood. They wondered what would happen to their children in the future and wanted information and support to assist their children through this process. According to Amina:

> *As they grow older, you know their behaviour changes, so how can we [deal] with them, this is the kind of information I require (Amina, parent)*

Parents, such as Amina also recognised that both they and their children were growing older at the same time and thus their health and social needs were changing. This posed a challenge for the parents to deal with both their own changing health needs, including ill health, and that of their teenage children, which caused tension between them. Information and support was required by the parents to help them deal with this situation, according to Amina:

> *As our age grows, body system changes so then we have our own problems. So how can we handle them? How to talk and communicate with them? (Amina, parent)*

Disabled children are often not seen as posing additional challenges in adolescence because they are viewed and treated as children. Despite this, disabled children go through the transition from childhood to adulthood and experience some of the emotional and biological changes that occur during this phase (Riddell, 1998). Thus they, like their non-disabled peers, require information and support to deal with the changes that are taking place and similarly their parents require information to support them through this period. However, disabled young people's access to mainstream youth clubs, leisure and social activities is limited and thus access to such information that might be available is also restricted. The disabled children/young people's consultation in Leicester found that disabled young adults (who participated in the consultation) experienced a lack of information about transition from school to life after school (from childhood to adulthood).

They were unaware about the support and services that they could receive once they left school, such as with their care, education, employment and about 'independent' living (with support) and were reluctant to consider leaving their parents' and/or carers' home (Patel, 2004).

4.3.5.2 Information as empowerment of the disabled children/young people

The parents' views of whether their children should be informed about their impairment and service provision varied. According to Mr Patel, his son (Rajan) should be informed about his impairment and services that are available by the medical profession and social services, so that Rajan could explain his impairment to his teachers. This might help them to understand the support that Rajan might require and to provide this accordingly, rather than Mr Patel mediating between the teachers and Rajan. Mr Patel felt that Rajan should be informed about the aids and equipment that he is entitled to, so that he can assess whether he is getting all his entitlements and also choose the aids/equipment that he felt were appropriate.

Sharmila felt that Rajeev should be informed about his impairment, which would enable him to deal with this better:

> *Definitely yes. If he knows how things are, he won't be complaining all the time. He says why do I have this? Why do I have ...? Why do they do operation to me? (Sharmila, parent)*

However, some of the parents with children with cognitive and communication difficulties thought that their children might be unable to understand the information that was given to them. Farida felt that Imran/Faraaz should be given information, but went on to say that:

> *He doesn't understand anything. So they give information to the parents like, what is going to happen... (Farida, parent)*

Thus parents mediate between services and their disabled children for the information and services that they require (Read, 2000). However tensions occur when policy, such as direct payments, advocate that teenagers access services and benefits by themselves. However, some of the parents felt that their disabled teenagers did not have the understanding of the concept of welfare services and benefits to do this:

> *That's the problem, isn't it? In benefits too, that's the problem. They say that because he's sixteen, he must claim benefits, but he can't sign. If he doesn't even know how to hold a pen then how [is] he going to sign? (Farida, parent)*

Farida felt that services such as health did not take their disabled children seriously, which is demonstrated by the medical profession:

> *...Taking too long to diagnose illness. If they treated special needs children quickly in the hospital or at the GP then we know. In this the parents suffer and the child suffer (Farida, parent)*

However, disabled children/young people require information, advice and support in their preferred methods of communication to understand and make decisions about concepts such as services and benefits, including health services. The Ask Us! video, made by disabled teenagers shows that they prefer to be communicated with directly and be part of decision-making processes that affect their lives (Willow, 2002).

4.3.5.3 Information about service provision

A finding in this study is that information about impairment and service provision was uncoordinated. There was an absence of a key worker and/or a professional designated with this role, and consequently some families were informed by a range of professionals about a variety of available services and benefits, whilst others missed out. For example, parents such as Amina were generally satisfied with the information and services that they received, whilst Mr Patel was critical, because he felt that the professionals informed him about the services that they thought he was entitled to rather than all the services that

were offered. Thus he was unable to ascertain whether he was receiving all the services to which he was entitled.

The access of disabled children and their parents to services often depends upon referrals. Some services permit self-referrals, whilst others prefer referrals to be made through other services. Thus the system of referral is often ad hoc resulting in some families having intervention from more services than other parents (discussed in chapter 6). This has an impact upon the parents' knowledge about welfare services and benefits and those parents without this information can lose out on valuable resources. Maya explained that she was unaware that she was entitled to child benefit, when she arrived in this country. By the time she became aware and applied for this she had lost out on unclaimed benefits. Thus immigrant families are likely to miss out on benefits that they are unaware of and uninformed about, because these are often assumed to be common knowledge.

Information about accessing resources such as popular books and games was also lacking. Sharmila found that the major high street shops did not stock books in alternative formats and she was unaware of how to access these. Thus information about accessing books and games in alternative formats was required, as was making this available in major shops, so that disabled children and adults can access mainstream shops rather than special outlets.

4.3.5.4 Future care

The majority of the parents were concerned about the care of their children in the future, when they were unable to do so, because their children might outlive them. Some of the parents reported an awareness of the institutional care that might be available, however, this was not considered a viable option for all. Maya expressed awareness about independent living:

> *In some places there is independent living, they live on their own and have someone to look after them as well. Who knows after he is 20 years old, if he could do things for himself it would be good. His life would become easy if he could look after himself (Maya, parent)*

However, not all the parents were as optimistic, Amina was concerned about Malka because she was a woman and therefore felt it inappropriate for her to live in a residential home. This could be due to Malka's vulnerability to abuse, as a disabled woman, and issues arising from a preference of some parents (and users) of same-gender based care. According to Amina:

> *We are worried because she is [a] girl. While I am here it [is] not a problem but when I am not here [when] I die who will look after her? This I am worried about because we had a girl (Amina, parent)*

The above reveals that the South Asian parents' ability to plan for their disabled children's future is restricted by a lack of information regarding the stability (or worsening) of their children's impairment and the services that might be available to assist their children in the future. Information provision regarding this would reduce their anxiety regarding their children's future and also help them to make informed decisions about their future care. Parents also require information and support for their children to be provided in such as way so that they could play a vital role in mediating for their own support services.

4.3.5.5 Impact of lack of information

Parents who wish to support their disabled children are disempowered by a lack of information (in appropriate languages and formats) about their impairments. The fact that information can empower is demonstrated by some of the mothers in this study, who were informed by a range of service providers and by the support groups that they attended. Some of the mothers increased their knowledge and self-confidence by attending courses at the support groups, and voiced their views about services as representatives on some of the committees. Information and knowledge about how to approach service providers can help with accessing the services that are provided, as demonstrated by Naseem Banu, in this study. Naseem Banu wanted

information about local information and advocacy services and also a social worker. She acted upon information that was forwarded to her about the service providers to contact and how (by me, as part of the research). Subsequently, Naseem Banu had contact with a social worker and information about the services to which she was entitled. However, for the majority of the South Asian parents in this study, their mediating role in securing the support their children required was restricted by a lack of knowledge about services and the way that service providers interacted with them. For example, regarding education, some of the parents were unaware of support that could be offered with their children's Statement of Educational Needs (SEN) by the Parent Partnership Officer. Those parents who were aware of this service did not know how it could have benefited them and an explanation (by me) about the possible benefits resulted in almost all wanting information about the service. However, accessing information was difficult because the services that were contacted claimed to have sent the information to the parents when their children had SEN statements. They were, therefore reluctant to send information packs to me and wanted the parents to contact the services directly. This shows that parents might not understand the significance of services about which they receive information and require explanations about their potential benefits, which did not seem to be happening. Parent Partnership Services, became statutory from January 1st 2001, within the SEN Code of Practice 2001, and are designed to ensure that parents of disabled children with SEN have access to information, advice and guidance regarding SEN issues so that informed decisions could be made (DfES, 2002). However, parents including South Asian parents will need to be informed about this and understand it to access this service.

Overall the lack of knowledge about services limits the parents' ability to mediate effectively for services for their disabled children and is compounded by the lack of commitment of services to provide maximum rather than the minimum support that is required by the child. The cumulative effect of this upon the child is insufficient support, which could result in different outcomes for the child who is well supported compared to those who were not.

Disabled children/young people are further disadvantaged because information about their impairments, treatment and services is provided to the parents rather than the disabled children/young people as the actual users of the services. Consequently, they are uninformed about their impairments and how to challenge decisions and treatment that they feel might be inappropriate.

Summary

The parents' experienced a lack of information regarding their children's impairment, and the services that might be available in the future, which inhibited their ability to plan for their children's future. Those parents who received intervention from a wider range of services were better informed, which was useful in the absence of a key worker and co-ordinated information and support services. Despite having both negative and positive experiences of the services, the parents agreed with the views of the services providers and professionals regarding ways in which their children's impairment could be improved. The services seemed to be applying the individual/medical model of disability, in which disabled children were seen to be at 'fault' and thus to be corrected with medical treatment and/or rehabilitated to be like non-disabled people. Thus services and professionals were a major influence on how the parents perceived their disabled children and interacted with them. For example, their view that there is something wrong with the child that needs to be corrected, rather than questioning the social barriers that prevent disabled children's inclusion in mainstream life.

4.4 Discussion and Conclusion

In this concluding section the main analytical points that emerged from the previous sections are discussed further in the following sub-sections:

(4.4.1) Parents' Perception about disability – how are they shaped?

(4.4.2) Models of interaction – that the parents applied

4.4.1 Parents' Perception about disability – how are they shaped?

An important finding is that to the parents in this study their disabled children were children first, but their experiences of parenting their disabled children were different because they were treated differently. This was due to the attitudes of individuals in society and responses of services to disability, which reflected disabled people's structural position in society – their general exclusion from mainstream life and activities. Although the parents were asked questions about social experiences (participation), they tended to focus on impairment. The following experiences shaped the parents' perception of disability, and influenced their interaction with their disabled children:

- Attitudinal responses, such as being 'stared at' by individuals in their own communities and wider society, and a lack of support with their disabled children when required.
- Support for parenting their disabled children was varied and those who are not well supported by members of the extended families could miss out on support from service providers, who might assume that all South Asian families are supported by members of their extended families and communities. The mothers in this study were the main carers of their disabled children and some professionals suggested that some of the mothers, (such as Shanta), should give up work to care for their disabled children, which reinforced the perception that caring and domestic tasks are a 'natural' remit of women's role in the home. The pressure that women were under to care for their disabled children and additional members of the family thus went unnoticed, which is evidenced by the lack of support that was offered and/or provided to these parents and those who might have benefited from external support.

The government has recently acknowledged the role of parents in caring for their disabled children as valuable. This could be because it could help with reducing the cost of care that could be borne by statutory bodies if the parents (mothers) insisted on attending work in preference to looking after their disabled children.

- Another aspect is the under use of short-break services by the parents because of a) the view that short-break services might be culturally inappropriate and b) breaks in which disabled children spend time away from home, particularly overnight, is considered (by parents such as Farida) as treating the disabled children unfavourably in comparison to their non-disabled siblings, who are not sent away for short-break services.
- A lack of information regarding their children's impairments and service provision, which hampered their efforts to support and care for their disabled children. The lack of information about the future care of their disabled children also prevented them from planning for their children's care in the future. This was particularly important for those parents who did not have aspirations for their children to be self-sufficient through employment and also to care for themselves. Therefore these parents were happy with the teaching of social and life skills (rather than academic subjects) to their disabled children because it could help them with their care. However, two of the parents did have career aspirations for their disabled children.
- The South Asian parents' (like their indigenous counterparts) experienced uncoordinated information and service provision, which added to the pressure of supporting and caring for their children effectively. The reasons for a failure to provide co-ordinated information and services could be:
  - The difficulties in multi-agency/disciplinary working. Sloper et al (2003) argue that key worker schemes could only be successful if they are provided in a multi-agency context, because services to disabled children and their families are offered by a range of services who need to work together to provide co-ordinated services. This is not happening because of the disciplinary and budgetary differences between various services (Read and Clements, 2001; Audit

Commission, 2003a; Treasury Department, 2003), which require compromise and negotiation so that services could be improved for disabled children and their families.

- The desire by services and professionals to guard their information and thus retain their 'expertise' in their disciplines, because disclosing information to other services and professionals could dilute individual professional's 'expertise'. Whilst informing disabled children and adults and their carers could result in their empowerment and lead to them asking questions and demanding better services.
- Increased knowledge (through a co-ordinated and appropriate information service) equals increased demand for service provision that some services are unable to meet. Information is not seen as vital, but an add on, particularly for people who require information in different languages and formats. Overall the lack of knowledge about services limits the parents' ability to mediate effectively for services for their disabled children and is compounded by the lack of commitment of services to provide maximum, rather than the minimum support that is required by the child. The cumulative effect of this upon the child is insufficient support, which could result in different outcomes for the child who is well supported compared to a child who is not.

- The parents (such as Farida) of disabled children/young people with cognitive and communication difficulties considered them to be unable to understand information regarding welfare and services and therefore preferred to be informed themselves, rather than their disabled children. This means that these disabled children/young people are uninformed about their impairments and the mechanisms to challenge decisions and treatments that they feel might be inappropriate. However, the parents of visually impaired children such as Mr Patel felt that disabled children such as his son should be informed about their impairment and services so that they could make decisions about the services (aids/equipment) that they require and want, rather than rely on the professionals' judgement.

4.4.2 Models of interaction – the models that the parents applied

A major finding is that the parents' response to disability and their interaction with their disabled children reflected the individual/ tragedy model of disability (of which the medical model is a sub-set), which was demonstrated in the following ways:

- Belief in professionals as 'experts' regarding their disabled children's impairment resulting in medical treatment being viewed as a solution to disability. This is demonstrated by the parents' quest for their disabled children to be like non-disabled children, through the improvement of their impairment by medical treatment and rehabilitation. The parents' interaction with social services and education reinforced the model held by both sides of rehabilitation, that focused upon the adaptation of the disabled children to the 'norm', thus not respecting who they were but who they should be and emulate to be (non-disabled children).
- Protectiveness and supervision of their disabled children. The parents were anxious about their disabled children's vulnerability to abuse in society and ensured that they were supervised and 'escorted' (McConkey and Smyth, 2003). This suggested a lack of trust in their disabled children's ability to take care of themselves, which is likely to be internalised by the children who consequently doubt their own abilities. However, the parents' anxiety about their children's vulnerability to abuse is not unfounded, because of the fact that disabled children and adults experience greater levels of abuse in their own homes, institutions and wider society because of their disadvantaged position in society (Asch and Fine, 1997). They are unlikely to be believed when they report the abuse that they experience and sometimes do not have an alternative to putting up with the abuse (ibid). Morris (1998a) argues that disabled children with cognitive and communication difficulties are generally unaware of the vocabulary by which to report discrimination and abuse, and they are not made aware of such issues due to the assumption of their inability to comprehend such concepts. This leaves them open to potential abuse, often without recourse.

For some disabled children/young people protection extended to possible denial of information and access to sexual and marital relationships (and possible parenthood). This was because their parents' doubted their disabled children's ability to comprehend the concept of marriage and parenthood and also their competence in maintaining these. Strategies to prevent sexual relationships of disabled people have included the segregation of men and women, the forced sterilisation of women, and extermination of disabled people (Pfeiffer, 1994; Rieser, 1995; Hubbard, 1997; Oswin, 1998). More recent methods include pre-natal testing of parents (usually women), the abortion of foetuses, vaccinations against illness and disease such as Rubella, and the Human Genome Project (Fryer, 1984, Pfeiffer, 1994; Barnes et al 1999; Hubbard, 1997; Oswin, 1998; Asch, 2001). The message this conveys to society, to parents and the disabled children and adults is that to be disabled is undesirable.

- Lack of awareness of the Social Model. This could be because the parents were mainly in contact with specialist 'disability' services, which seem to project the individual/medical model of disability.
- Isolation. The parents' and their disabled children's response to societal treatment of disability was to impose self-isolation and thus compound the exclusion imposed by the treatment of disabled children in both their own communities and wider society. The message this conveys to society and their disabled children is that their children are different and should be segregated from the majority. To be included in mainstream activities, disabled children have to be accepted by non-disabled people (Quinn, 1998) as having adapted to the standards that are set by them, such as attaining education, employment and thus economic contribution to society. By doing this, individuals are considered responsible and progress to social and marital relationships. However, for disabled young people this is a dream because of the barriers they experience in support services, education, training, employment, leisure and social life. Therefore they are less likely (than their non-disabled peers) to be in employment and social relationships

that are considered in society as the bedrock of contributing both financially and socially to society (Riddell, 1998).

In conclusion

The disability movement's thrust to change the social attitudes to disabled people by projecting the view that it is societal and environmental aspects that prevent disabled people's participation in mainstream life rather than their impairment, did not seem to filter down to the South Asian parents' experiences. Rather they encountered traditional attitudes towards their children's disability on all sides from the medical profession, education, social services and members of their own communities that reinforced the individual/medical model of disability. This attitude, which considers the individual as 'defective' and examines ways to correct this, was internalised by both the parents and their children. This is evidenced by the parent's approval of medical treatment and rehabilitation, which aimed to make their disabled children like their non-disabled peers and the way in which they interacted with their disabled children.

A major finding is that the parents' described their disabled children like other (non-disabled) children and not as disabled children, but they experienced differential treatment because of the institutional discrimination (disability and racism) in service provision and society. Furthermore, the social exclusion that is experienced by the disabled children also affects the parents and siblings of disabled children. However, like other parents of disabled children they experienced uncoordinated information and service provision which had an impact upon the resources that they had access to in order to:

- Support their disabled children.
- Mediate between services, society and their disabled children.

CHAPTER 5 SOUTH ASIAN DISABLED YOUNG PEOPLE'S EXPERIENCES

In this chapter the South Asian disabled children/young people's experiences are presented and analysed in the main sections stated below.

(5.1) Disability and difference

(5.2) Family and friendship

(5.3) Looking towards the future

(5.4) Discussion and Conclusion

The data presented in this chapter provides an insight into the experiences of the young participants such as Ajay, Jamila, Imran/Faraaz, Malka, Rajan and Rajeev, which makes this study important. This is because their experiences and the process of accessing their views is unique and provides a platform for other researchers to build upon this information in future research.

Access to the young participants was gained through their parents, because in my experience as a South Asian woman I was aware that in South Asian cultures in general and some families in particular, the relationship between parents and their children is interdependent. This means that in matters concerning their children some South Asian parents expect to be approached prior to their children, which makes accessing the children directly difficult. I was also aware that the parents of disabled children have knowledge about their children's preferred methods of communication and characteristics that would have helped with approaching the children and also with data collection.

In terms of the data, out of the seven South Asian disabled young people who participated, two (Rajan and Rajeev) responded more fully to the questions asked, and therefore the greatest amount of data was received from these interviews, particularly from Rajan, which is mainly presented in this chapter. The rest of the participants (Ajay, Jamila, Malka, Imran/Faraaz) gave yes/no or short answers to some of the questions that were asked, used body language such as nodding/shaking their heads and Makaton (and/or gestures).

The following example from Malka's interview illustrates this (in Malka's (M) interview the facilitator (F) asked the majority of the questions):

F: Can you tell me a bit about yourself? M are you a girl or a boy?
M: Girl
F: And what's your name? Can you tell me your name?
M: My name is XX
F: Very good. What does M like doing?
M: Home, Playing
F: Playing with what? Teddy or doll? Have you got lots of dolls or just one?
M: One
F: Just one, Oh! Have you any other toys?
M: Mum, Dad
F: Mum and dad are at home aren't they? How many sisters have you got?
M: Two

Ajay also used a communication device in two of the interviews. These participants also did not respond to all the questions asked and offered information that was not related to the questions asked. The questions were tailored according to the individual and therefore the same ones were not asked in all the interviews, but were located under the main subject areas. Yes/no and short answers resulted in a lack of descriptive data in the participants' own words. Using data, which was derived through the facilitator was also difficult because in some cases leading questions were asked, and/or because responses were encouraged. Where possible the data from the disabled young participants' interviews is used and it is also complemented with observations made during the interviews and also from the parents' data as relevant. Only one participant (Kamini) did not respond to any of the questions resulting in a lack of data, apart from the information given by her mum.

This chapter is not representative of the experiences of all South Asian disabled young people, but offers some insight into the experiences of Rajan and Rajeev and also in some ways Ajay and Jamila, of living in an environment that is designed for the majority – non-disabled indigenous people.

It also describes an environment, reflecting the dominant social structures in society, in which those with power such as service providers have the greatest access to mechanisms such as research to represent their views, followed by the parents and then by the disabled children and young people who have the least amount of power. This is due to factors such as age, which is compounded by disability, racism, sexism, sexuality and class. By aiming to include the disabled children/young people's participation in the research, a process was started that could be built upon by other researchers in the future. For example, by considering methods via which data could be collected over a longer period of time.

Pseudonyms were used for the participants (stated in the table below), and these were chosen either by their parents and/or me at the interview stage, and agreed by the South Asian disabled young people. Only one participant chose an alternative.

Table 16: Pseudonym - Age and Gender of the South Asian disabled young people

Name	Age	Gender
Ajay	15	M
Imran/Faraaz	15+	M
Jamila	12	F
Kamini	14	F
Malka	15	F
Rajan	12	M
Rajeev	7	M

5.1 Disability and difference

> *Well it's like don't go near him, might catch something and I'm like doesn't matter, just being silly. You know I just tried and tried to persevere really (Rajan)*

The South Asian disabled young people, like their non-disabled peers, enjoyed participating in activities pertinent to their age group such as leisure activities, music, going out, watching TV and video. Therefore these South Asian disabled young people were the same as their non-disabled peers, yet their experiences were different because they were defined by disability, and as a result treated differently.

Disabled children and adults are considered to be a homogenous group despite the fact that individuals experience disability differently, which is influenced by factors such as age, class, gender, sexuality and ethnicity. Some people are diagnosed at birth whilst others are diagnosed later in life and would have experienced life as a non-disabled person (French, 1994). In this study 5 children were diagnosed when they were under a year old and 2 (Rajan and Rajeev) when they were about 5-7 years of age. Therefore Rajan and Rajeev experienced life as non-disabled children prior to diagnosis. However, as a result of diagnosis they experienced differential treatment because of being defined as disabled, as described by Rajan:

> *Like has just changed, wearing glasses. Everyone looks at me in a different way, it's scary. One minute I'm OK, next minute you know (Rajan)*

Rajan experienced a dramatic shift from being identified as a non-disabled person to a disabled person and subsequently was viewed with fear by some people and as requiring assistance and care by other people.

> *Some people think they can catch it, you can't catch it, it's in my eye. I had some friends, quite a few people [who] help me with things (Rajan)*

Rajan explained that some of his friends helped him, were kind to him and looked after him. In doing so they helped to enact the role of dependency which disabled people are expected to adopt:

> *Like if I can't see they tell me what everything means, and if a step is coming they tell me to watch out, and if I want to read something and I can't [see] I ask them to read it to me. Pictures even TV sometimes, I can't see that. Little thing like that they help (Rajan)*

Not all the participants expressed an understanding of disability, however their experience of differential treatment could be gleaned from observations during their interviews and their parents' interview data. For example, in the previous chapter, Zaida explained that Jamila did not like to be with other people who had a similar disability and also did not like to see pictures in magazines of other people with a similar disability. Jamila was also aware that she did not attend the same school as her sibling and preferred her own company, often resulting in self-imposed isolation. Malka (according to her mum - Amina) was aware of other people looking at her, when she went shopping with her family, which suggested to her that something was wrong with her. Imran/Faraaz (according to his mum - Farida) was aware when he was bought different items of clothing and equipment to that of his siblings and insisted on being bought the same items. For example, he was given a toy mobile phone rather than the actual mobile phones that were given to his non-disabled siblings. The message that is conveyed to these South Asian disabled young people through the media (magazines), society and family is that they are different to the majority.

Swain and Cameron (1999) argue that disabled people are defined by non-disabled people and compared to them, and that social comparison between disabled and non-disabled people is not about social characteristics but of social structures in which one group has the power over another. Disabled people, particularly, those with cognitive and communication difficulties are considered incapable of making decisions for themselves, which are therefore made by non-disabled people on their behalf (Morris, 1998c).

This is reflected by the tendency of professionals and also researchers to communicate with the parents and carers rather than with the disabled children/young people directly (Triangle, 2001; Cavet 1998b).

In general, the communication that occurs with children/young people with cognitive and communication difficulties is based upon closed questions, from which a yes/no response is usually derived, rather than a dialogue through discussion. This can restrict awareness of issues pertinent to the experiences of adolescents such as sex, relationships, bullying and abuse (Morris, 1998b), which can be developed through discussion (Adams and Ingham, 1998). Limited communication can inhibit the understanding and naming of important social experiences such as discrimination and abuse to which disabled children/young people are vulnerable. In this study, only one participant (Rajan) talked about unhappy experiences and being bullied at school because of disability, the rest did not mention such experiences and/or indicate awareness about bullying, disability, racism, sexism and/or abuse. Some of the reasons for this could be:

- Participants were not asked direct questions about their experiences regarding disability and racism. Whilst Rajan talked about disability he did not mention racism.
- Discrimination and abuse may be something that the participants feel they have no control over and/or might not be believed about and consequently they might not give it much thought or talk about it.
- Special schools might project an image that they are a safer and happier environment in which aspects that cause unhappiness are not talked about (my conversation with a facilitator – professional).
- The presence of the facilitator might inhibit sharing of unhappy information. The facilitator might also be the perpetrator (abuse, bullying and discrimination) of the young person's unhappiness.
- Some disabled young people may not have the awareness to name negative experiences.

5.1.1 Bullying

They say horrible things to me and sometimes it's too horrible (Rajan)

Existing literature (Quinn, 1998; Robinson and Stalker, 1998; Middleton, 1999; Connors and Stalker, 2003) shows that children and young people who do not 'fit into' the status quo because of gender, ethnicity, and disability are likely to be bullied. Rajan experienced the following at school:

> *Before, we used to, like, we have like a rack to put our bags and my rack is on the bottom and when I bend down to get my bag, they've got their bags at the top, they drop it on me. I sometimes think that because it is higher they could drop it by accident, but I don't know what they're doing do I? They might push me and say sorry, but did it on purpose, but I could tell by how they act. They think they can talk behind my back and say stuff, but it I'm not far away I can hear, I can't see that well, but it doesn't mean I can't hear, I've got good hearing (Rajan)*

Bullying occurs at several levels and can be perpetrated by disabled and non-disabled children/young people and adults such as relatives, carers, practitioners and professionals (Westcott and Cross, 1996; Asch and Fine, 1997; Middleton, 1999). This is illustrated by the example below.

During an observation that was conducted at a statutory establishment for disabled children and young people, which began in the morning and ended after lunch break, several incidents, which could be defined as bullying, occurred. The incidents involved Ajay (South Asian disabled young person and participant in this study), who was being observed, and occurred in the following order:

- During the morning session in which disabled young people and professionals including Ajay were involved in viewing a video of a recent residential trip. Ajay was 'told off' by a teacher (white) in front of his disabled peers and other staff members for interrupting the session. He was told to apologise for interrupting the activity, which he promptly did. As result of this interaction, Ajay looked 'cowed' and was quiet for the rest of the session, although on occasions he tried to say something and at those times another

disabled young person (white) pointed at him and said "*down*". This seemed to be accepted by the people (teachers, care assistants, other pupils) present in the room and demonstrates that children/young people could be influenced by adult behaviour. This transmits the message that such behaviour is acceptable. However, whilst Ajay was 'told off' for interrupting, his disabled peers who also interrupted during the session were not, resulting in differential treatment of pupils.

- There seemed to be some favouritism of some disabled young people by the staff. For example during the lunch break Ajay requested a drink of coke, which he was refused, and yet another disabled young person (white) helped himself to a drink of coke, which seemed to be acceptable. It could be that Ajay's diet did not permit coke, but the refusal of coke was not explained to him.

- During lunch break, Ajay was on his own waiting for his lunch, which was being prepared, when another disabled young person (white) 'thumped' him on his back with some force, without any provocation. This was noticed by a practitioner who proceeded to tell this person 'off', but no other action seemed to follow.

In a short space of time 3 incidents were observed which occurred at different levels, yet Ajay did not mention these during the semi-structured interview that was conducted immediately after lunch. This could be because:

- It might be a common experience, which he was used to.
- Ajay was unaware of how to name such incidents and thought he might not be believed.
- He did not wish to talk about the incidents with an unfamiliar person (me) and/or in the presence of a facilitator (white) who was also a member of staff.

If incidents of bullying and abuse that disabled young people such as Ajay experience go unreported then these could not be addressed. The above observation of the experience of one South Asian disabled young person begs the question of how many incidents of bullying take place which are not disclosed, reported and/or addressed. The above example illustrates that the power of being part of the status quo (ethnicity, disability, age and status) can be exercised over one group and/or individual over another. Consequently, individuals who are being bullied by those who are part of the status quo due to factors such as ethnicity, disability, age and status (such as the teacher) might have difficulties in challenging this situation. However, incidents that are reported might not be addressed satisfactorily, which could deter disabled young people, such as Rajan, from reporting future incidents. According to Rajan:

> *Yes, they [teachers] try and sort it out, they can't say don't be horrible, well they can, but it doesn't mean they listen to the teachers. You can tell as much as you want or their parents, but it's up to the person at the end of the day (Rajan)*

It seems that establishments that are supposed to provide a safer environment for disabled young people such as Rajan and Ajay fail (Westcott and Cross, 1996; Asch and Fine, 1997; Middleton, 1999) to protect them from discrimination and abuse, and could also perpetuate and reinforce it. This could be because disabled children/young people are generally undervalued in society (Morris, 1998b) due to age and disability, which could be compounded by ethnicity, gender and sexuality. This means that disabled young people, such as Ajay's, inclusion in life is conditional upon the acceptance of abuse in their lives as being a 'normal' part of their experiences and therefore to be accommodated into their lives. From a Social Model perspective, disabled young people such as Ajay experience abuse as part of their lives on several levels, which present a barrier to full integration in mainstream life.

5.1.2 Wanting to be 'normal'

> *I wish that my life went back to 'normal', my eyes were like 'normal' eyes and not to have these problems and be independent (Rajan)*
>
> *I could see with both eyes (Rajeev)*

Disabled young people want to be like their non-disabled peers so that they could participate in mainstream life without experiencing the difference that they experience as disabled people. In this study both Rajan and Rajeev wished to have "*normal*" eyesight, which would enable them to be part of the status quo. Rajan associated his experience of disability with problems and dependency and envisaged that if his impairment disappeared so would his problems. Non-disability was linked to independence and having choices in their lives, which are generally denied to the disabled young people because of the social barriers that they experience. The feelings that disabled young people experience as a result of differential treatment include confusion, helplessness, unhappiness and uncertainty as explained by Rajan:

> *...You know at school yeah, sometimes I've had enough of it, just want to get away from it yeah and someone said this to me and I thought – had enough. Like before I even felt depressed like, why do people do this to me? It's not you know fair. Why are they just picking on me, there're other people as well? I just come home and just sitting. Sometimes I used to cry. When I was little I didn't understand and everything, so I just thought you know what am I going to do? Am I going to be like that for the rest of my life or something? I still don't know if [I am] going to be like this in my life, they said it should get better but don't know, not exactly sure (Rajan)*

Rajan received confusing messages about disability because he was informed that he was different to the majority and therefore treated differently, but also that he needed to fit into 'normal' life. Rajan and also Rajeev wanted to be like their non-disabled peers to be part of the status quo and reduce the differential treatment that they experienced. Medical intervention and rehabilitation are ways in which disabled children/young people are corrected to 'fit into' the status quo. For example, all the South Asian disabled children/young people in this study received medical intervention (in varying degrees).

Whilst medical intervention could provide relief from pain caused by impairment, it could also be painful and was primarily used to correct and/or cure the impairment to 'normalise' the individual, which is seen (by parents and the children themselves) as worth it if it works. For example, Rajan said that although he found medical intervention painful he put up with it because it might make his impairment "*better*", and he also hoped that there might be a cure for his specific impairment in the future. In terms of his experience of medical intervention Rajan expressed:

> *I'm just fed up about it. It's like, now they just send you a letter every two years to come down, but before it used to be every single week, and it's like go away, some other doctor shining [light] in your eyes, [putting] 20 drops in my eyes, is this going to make me go more worse? How many drops in your eyes, how bright [is the] light, when I've sat and looked at I can't see anything else (Rajan)*

Disabled young people's, such as Rajan's experiences of medical intervention needs to be considered within the context of the medicalisation of disability (Oliver, 1990) and the view that disabled people are 'imperfect' people until they are like non-disabled people (Finkelstein and French, 1993). This is conveyed through perceptions and actions of carers, parents, professionals, service providers and the media (discussed in chapter 4). For example, parents with disabled children are informed as soon as their child is diagnosed, about possible medical intervention that might cure and/or correct the impairment. If this fails they are then informed about the ways in which their disabled children could be adapted to fit into 'normal' life. The South Asian parents in this study (such as Mr Patel) sought a second medical opinion, hoped for a cure for their children's impairments and approved their children's treatment. These strategies involved the disabled young people in diagnosis, medical examinations, and possible treatment, which confirmed to them that there is something wrong with them and until they are 'corrected' they will be 'imperfect'. This is a view that could be internalised by the disabled children/young people.

5.1.3 Support

> *When I can't see he helps me and if someone is not kind helps a lot since this happened to me (Rajan)*

The notion that to be disabled is to be cared for is also internalised by disabled young people. Both Jamila and Rajan talked about being "*looked after*" by their (non-disabled) siblings. Rajan also mentioned friends, family and teachers who helped him and were kind to him:

> *My brother, my dad, friends are kind to me, teachers are really kind and help me a lot. My granddad and then there are some people I don't really like, some people in my class who are really horrible (Rajan)*

However, both Jamila and Rajan liked to be independent. For example, Jamila liked "*bathing and washing her hair and going shopping*" by herself. Rajan liked to be independent (to do things by himself) and would only seek support if required. However, environments and equipment designed for the majority can be inaccessible to disabled young people, who rely on other people to support them to access these. Rajan explained that sometimes he was unable to read the cards that are included in board games and the information on the Internet because of the small font that is used. Consequently, Rajan had to get someone to read these for him and he felt that manufacturers and Internet designers did not think about how disabled people could access these:

> *Sometimes it could be problem, but I'm coping with it. If I want to do something I have to see it, like playing a board game I can't see it maybe because it has small cards to read and stuff or if I'm on the Internet I need to call someone to help. Some people they don't think about if someone can't see it how would they adjust the website or how would they make it bigger (Rajan)*

Rajeev experienced a different kind of frustration with the Internet:

> *No. I'd rather go on the Internet on different websites and I like to play at school, but the thing I hate is when you're doing research and you click on something, yea like games, it goes to Chinese websites (Rajeev)*

Aspects such as font size and access to websites could be rectified by making information (including games, equipment, resources) available in numerous formats that can be accessed by people in their preferred methods of communication, rather than the dominant method used by the majority – speech and print in the English language. Access to different formats are usually specialised and separated from the majority with different access points such as specialised outlets and services, which are often inaccessible to disabled children and their parents. This is because they might not have the information, knowledge and funds to access specialised outlets and services. Accessible information could help with enabling increased independence of disabled young people such as Rajan.

Jamila's and Rajan's wish to be independent shows that South Asian disabled young people are confident in their abilities, in a similar way to the disabled young people in McConkey and Smyth's study (2003). However, other people (such as parents and professionals) doubt their abilities because they are compared to the majority. For example, whilst Jamila liked to conduct personal tasks herself, Zaida (her mother) felt that it was not up to her standard and that Jamila took too long and therefore assisted her. Zaida was also apprehensive of Jamila going to the local shop on her own, although she realised that Jamila needs to do that, as she grows older. Parents experience tension in achieving a balance between protecting their children and enabling their independence. This is compounded by parental apprehension about their children's ability to cope in unsupervised situations and their vulnerability to abuse. Over-protectiveness of disabled children can lead to 'infantilisation' (Hockey and James (1993), in which they are considered children for a prolonged period, resulting in a shorter period for transition to adulthood. Parental protectiveness can restrict disabled young people's access to social and leisure opportunities that their non-disabled peers access (Bignall and Butt, 2000a). Yet the interaction with disabled and non-disabled peers can enable disabled young people to raise their awareness about issues that affect their lives and improve their social and communication skills.

However, for disabled young people their access to social and leisure opportunities is also inhibited by societal attitudes and inaccessible environments resulting in their isolation (Cavet, 1998a; Middleton, 1999; Watson et al, 1999; Bignall and Butt, 2000a; Morris, 2001).

5.2 Family and friendship

The South Asian disabled young people who participated in this study, lived in two-parent heterosexual families and all had siblings. None of the parents were disabled, although three of the young people had disabled siblings. However, 4 of the South Asian disabled young people were in the company of mainly non-disabled people at home. As a result they were advised and supported by parents and siblings who had a subjective understanding of racism, but not of disability and the multiple-identities that are experienced by South Asian disabled children/young people. Consequently they, like their other disabled peers, also lacked the opportunity to interact with people with similar experiences to them in their family setting. This could inhibit them from forming a view of the world as South Asian disabled young people (who experience racism and disability) through different experiences, which are complemented by the learning that takes place at school, socially and within the home. For example, discussion with disabled peers about issues that are relevant to their age group, such as sex, contraception, bullying, racism, recreational and leisure activities and exclusion, raises their awareness about such issues. This can also lead to awareness of their social position and working out solutions with their peers.

The South Asian disabled young people in this study had friends, although there was a difference regarding the avenues that were available to them to make friends and interact with their peers. Those participants who attended special schools and colleges tended to have other disabled children/young people, mainly their classmates, as their friends. There seemed to be little interaction with their friends outside the school setting.

The special schools and colleges that the disabled young people attended were located outside their local vicinity, which meant that the disabled children/young people travelled outside their neighbourhood, often in transport that was provided. It seems that these disabled young people also had fewer opportunities of making friends with their peers en route to school and/or college and had fewer friends in their locality, because their movement was supervised by adults, which could limit their interaction with non-disabled peers within the neighbourhood, thereby resulting in isolation and invisibility. For example, Jamila, (according to her mum - Zaida) was permitted to play with the neighbour's daughter, at their house but not at the neighbour's house. This was because Zaida did not want to '*burden*' other people with Jamila. Yet this could restrict Jamila's interaction with her non-disabled peers and other people in her neighbourhood. This could also result in disabled young people, such as Jamila spending time on their own and/or with their families.

What you can do matters in making friends

The disabled young people, who did not have cognitive, communication and mobility difficulties, had greater autonomy to participate in the local neighbourhood and in activities with their non-disabled peers. For example, Rajeev was the only participant who had a lot of friends in the neighbourhood who all attended other schools to the one he did. Rajeev was able to '*hang about*' in the neighbourhood with his friends, which some disabled children cannot or are not allowed to do. According to Rajeev:

> *One thing I like is that all my friends who live round here. Their houses are next to each other (Rajeev)*

However, Rajan played with his sibling and his cousins and not his peers from his school because "*...they don't actually come out anymore, they're always out somewhere" (Rajan).*

Reciprocity

Friendship is usually based upon reciprocity. For example, Rajan explained that his non-disabled peers were able to talk to him because he offered them empathy when they felt sad, listened to them, and maintained confidentiality, as the following quote illustrates:

> *Yeah sometimes when like if they're feeling sad or something, try to make them laugh because they sometimes, they are upset and just say not feeling well I go to them and talk to them because I know because even if I don't feel well I know [what it] feels like if they get treated like really…because I've had it before. If they want to tell me something then I won't tell anyone so (Rajan)*

Rajan used his experience of disability positively by empathising with his (non-disabled) friends when they were feeling unhappy and under-valued, although the causes that produced these feelings were different. Rajeev's (non-disabled) friends saved him a space in the games that they played and also helped him with his school project work:

> *Help me with my work and we are in partners, being my partner and stuff (Rajeev)*

According to Jamila:

> *Nice, like all friends. They play with me games. Both they like [you] and you like [them] (Jamila)*

However, not all disabled young people have the opportunity to establish friendships with non-disabled peers. Amado (1993) argues that non-disabled young people might resist making friends with their disabled peers because they feel that they might give more to the friendship than they receive from their disabled friends.

5.3 Looking towards the future

The South Asian disabled young people had a view of what they wanted to do in the future, which included attending college and/or university, paid employment, assisting their parent and travel and/or holiday abroad. Thus they had similar aspirations to their non-disabled peers about their future, which included paid employment, travel and holidays. However, a key difference between the disabled young people and their parents was their differing views about the future. For example, whilst the disabled young people had aspirations for their future only two of the parents had aspirations for their children's future.

There was also a contradiction between Rajeev and his mum's (Sharmila) view regarding future aspirations, for example according to Rajeev his mum wanted him to be a pilot but Rajeev wants *"to be scientist or archaeologist".* However, South Asian disabled young people's potential to achieve their future aspirations is different to their non-disabled peers, although similar to other disabled young people. This is because of the following barriers:

- The lower expectation that professionals and the parents have of disabled young people, particularly of those in special schools, to fulfil their potential.
- Experiences of disability and racism.
- Lack of relevant role models. For example, all the facilitators in this study were women and of these, three were the mothers of the disabled young people, one was a relative (cousin), and five were practitioners (1-professional, 4 - assistants). Two of the practitioners were of South Asian origin and employed in a city and county education establishment as assistants respectively, the rest were white.
- Another area in which there is a lack of positive role models is marriage and parenthood. In this study only one disabled young person said that he wanted to get married and another mentioned love. The rest did not mention love, marriage, and/or sex, which could be because:

- Views about this were not asked for by me
- The disabled young people might have limited access to information and opportunities to discuss these issues, particularly with their parents.

The South Asian parents' views (chapter 4) reveal that disabled children/young people with cognitive and communication difficulties are assumed to be incompetent to understand and maintain concepts such as marriage and parenthood. A key difference for the disabled young person who mentioned wanting to get married and his mum was her view - that her disabled son would not get married because of this perceived incompetence. This means that this young person's aspiration to get married could be unfulfilled.

Change

An area in which Rajan wanted change to occur, is in the way in which disabled people are treated by other people in society. According to Rajan:

> *I want them to think about it, what if I was like that, then they'd know not be so, I don't know (Rajan)*

However, not all the participants in this study were as politicised as Rajan regarding their view about disability. For example, Rajan was aware that disabled people were treated differently to non-disabled people and that this does not necessarily have to be so:

> *I think there is somebody with a hearing aid, there's all different people like that, but there's nothing wrong with them. It's just people look at them in a different way as if there is something wrong. OK, we know there's something wrong with them, but like some people can help and treat them like a normal person, just because we've got something wrong with us we get treated like a lower level and it's not right.*

The rest of the young participants might not have mixed with groups in which alternatives could be discussed. These disabled young people seemed to spend their time in environments (both educationally and socially) that were supervised by adults (professionals and parents) who were mainly using the individual (tragedy/medical) model of disability (discussed in the chapter 4). In the absence of an awareness of an alternative model (such as the Social Model) the disabled young people are likely to internalise their parents' and professionals' perception of impairment as a tragedy and a 'defect' requiring

correction and/or rehabilitation of the disabled person to 'fit into' 'normal' life, rather than adjusting the social barriers that prevent their inclusion in mainstream life.

5.4 Discussion and Conclusion

This chapter offered some insights into the experiences of some of the South Asian disabled young people who participated in this study, but the views presented cannot be generalised to a wider group of South Asian disabled young people. Rajan's views have been mainly presented followed by those of Rajeev, because they both responded to the questions, which resulted in the greatest amount of data. The other young participants (5) either did not respond to all the questions, or answered very briefly. They also preferred to offer information unrelated to the questions. Despite these caveats however, the views that were presented from the data of the interviews with the South Asian disabled young people (and their parents as relevant) suggest the following:

- Disabled children who are diagnosed later in their childhood (and not at birth) (such as Rajan and Rajeev) experience life as non-disabled children and have a previous non-disabled state ('normal') state to revert to, which disabled children who are diagnosed prior to and/or at birth do not have. Both Rajan and Rajeev wanted to revert to their initial non-disabled ('normal) state because they wanted the same opportunities as their non-disabled peers and not the experiences of difference and social exclusion that they encountered as disabled children. Rajan found his impairment to be a hindrance to his independence and to being part of the status quo. He therefore individualised this aspect as being a 'problem' for him, rather than the way impairment is viewed in society (as 'defective' therefore requiring correction or rehabilitation). This view was internalised by Rajan through the messages that he received from individuals in society, his parents and professionals.
- Being supported by family, friends and teachers was also part of disabled young people (such as Rajan's and Jamila's) lives who received the support they needed but also wanted to be independent.

However, there seemed to be a lack of awareness of the formal support (for example in education) that could be received by disabled young people. Rajan was the only young participant who was aware that disabled children/young people are supported in education through Special Education Needs. Rajan was also the only young participant to state that disabled people should not be treated differently to non-disabled people, rather that they should be supported. This could be because Rajan may have had opportunities to meet with a wider group of disabled and non-disabled peers with whom he could share similar experiences, such as other disabled people within his mainstream school, and also compare these experiences with those of his non-disabled peers. The disabled children who attended special schools may not have had such an opportunity at school and at home because they seemed to spend their time in supervised (adult) company, which could limit opportunities to interact with a wider group of disabled and non-disabled people.

- Bullying experienced at school was part of two of the participants' lives. In one case it was witnessed by myself, which suggested that bullying occurs on several levels and in both mainstream and special schools, and that disabled children/young people could be bullied by non-disabled and disabled peers as well as adults. For disabled young people, bullying will continue to be part of their lives and therefore a barrier to their inclusion in mainstream life if it is not addressed in a way that eliminates it from their lives. It seems that policies that deal with bullying need to ensure that disabled children/young people are enabled to recognise and name incidents of bullying and abuse, and are also confident to report them and that incidents are addressed in way that makes a positive difference in their lives.
- Family and friends were an important part of the young participants' lives. All the young participants had friends, although those who attended special schools had their disabled peers at school as friends and those who attended mainstream schools had non-disabled peers as friends, although Rajan had both non-disabled and disabled peers who attended his

In conclusion

The experiences of the South Asian disabled young people such as Rajan, Rajeev and in some ways Ajay, Imran/Faraaz, Jamila and Malka presented in this chapter suggest that they like the same things that their non-disabled peers do, but experience difference and social exclusion. The young participants were supported by their family and friends, and were unaware of the formal support (apart from Rajan) and anti-discriminatory legislation that could help them to access their rights and therefore citizenship.

In attempting to include the South Asian disabled young people's in this study a process was started in which their views could be sought and heard. It was identified that direct contact with parents prior to approaching the children worked as it helped to access the disabled young participants. Both the insights offered by the young participants and the process used to gain access to their views provides a platform for other researchers to build upon in future research. The process used in this study suggests that a longer-term study could help to gather data from disabled young people because this would allow:

- More time to build relationships with the participants and to learn their preferred methods of communications that could enable direct communication with them during data collection.
- Observation in different settings at different times.

CHAPTER 6 SERVICE PROVIDERS' EXPERIENCES

In this chapter, the findings from the interviews with the service providers are presented and analysed in the sections stated below.

(6.1) Services offered

(6.2) Specialist disability and BME services

(6.3) Solutions

(6.4) Models used by the services

(6.5) Policy

(6.6) Discussion and conclusion

Twenty-two service providers, comprising of statutory, voluntary and community organisations, as categorised in the table below, were represented in this study. The representatives were employed at director, managerial, policy and operational levels within their organisations and are coded as SP1 to SP22. The codes refer to the individual and the organisation or service represented. The names of the agencies, which participated in this study, are not listed in order to offer the representatives anonymity.

Table 17: Breakdown of Services that were represented

Organisation	**Number**
Education – Local authority (Specialist services for disabled children)	4
Social Services – Local authority (Specialist services for children/disabled children and adults)	2
Health – Statutory Health Authority (Specialist services for South Asian disabled children/carers)	1
Voluntary/Charity (Specialist services for disabled children and adults)	13
Community (Specialist services mainly for BME and South Asian communities)	2
Total	**22**

6.1 Services offered

The 22 services offered one or more of the following:

- Information and/or advocacy regarding specialist services and/or general services
- Short-break services
- Leisure and recreational activities
- Support and services in the home
- Rehabilitation, information and advice to parents and carers of disabled children and adults
- Education
- Social care

This illustrates the wide range of services that are available and likely to intervene in the lives of disabled children and their parents (discussed in chapter 4).

6.1.1 Funding

In general, the services were provided according to the funding and criteria of each service and to those service users who met the given criteria. Some of the organisations received funding from different sources. For example SP13 was:

> *Multi-funded, could be local government, Children in Need, Local Authority, Charity, run in the marathon for us and raised £1000 – lots of different grants, Coalfield regeneration (SP13)*

Funding from different sources enabled the organisations to provide a range of services to those users who met the different criteria stipulated by the funding agency, which resulted in different services being provided to the different users as the following examples illustrate:

- Transport was not provided to all the parents who attended a support group because the funding for the transport was for parents who lived in a particular area. Consequently, parents such as Shanta (parent, in this

study) who did not live in the given area were denied transport and, thus, access to the support group to which other parents, living in the other area, were allowed.

- SP13 was granted Sure-Start funding to provide services in the home for children who were younger than 4 years, and who lived in the declared Sure-Start area. This excluded those users who did not fit the criteria but might have required the same service and therefore a tiered service is created. This is because some of the users might be eligible whilst others might not, yet their need for services might be similar or even greater.

Funding was an issue that restricted both disability and BME service providers in providing services to groups such as South Asian disabled children and their carers, who require both disability sensitive and culturally appropriate services. Evans and Banton (2001) argue that because of limited funding, organisations are only able to provide services that they are funded to, and they are unable to expand their services. Consequently, services concentrate on the core function of the organisation such as providing services that focus on disability or ethnicity (ibid). They argue that funding is required to make services accessible and culturally appropriate (ibid). For example, to meet the communication needs of South Asian disabled children and their carers, provision of information in different formats and languages needs to be considered at the policy and planning stages, so that appropriate resources are allocated at the outset (Flynn and Patel, 2002). According to SP11 the lack of recognition of South Asian users' needs at the outset results in a lack of funding to deliver services that are appropriate to these users.

To bolster core funding, the service providers sought funding from different sources to assist with developing services. However, this is often short-term funding that prevents long-term developmental work. Voluntary and community organisations often compete for funds that are in the same pot, which can result in tension between different organisations and groups, because not all applications (organisations) are successful (Mir et al, 2001).

According to SP17, which provided services to BME communities, funding for expanding their services to disabled users was curtailed because a funding application to the National Opportunities Fund of a block grant for this purpose was unsuccessful, although they felt that they had met the criteria for the grant bid. BME community organisations compete with established voluntary and charity organisations (such as the RNIB), which have the capacity to implement fundraising strategies and a reputation for providing services, which some BME organisations might lack (Ahmad et al, 1998b; BTEG, 2003). Consequently BME organisations have greater difficulties in securing funding, because they might not have the organisational infrastructure, including knowledge about governance and funding sources that established organisations might have. For example, BME organisations might lack members with financial, managerial and policy experience and knowledge to inform the running of the organisation and also for making funding applications. This is a difficult area to discuss with community organisations because of the tragic nature of funding relationships between funding agencies such as Local Authorities, established voluntary sector and BME voluntary sector. McLeod et al's (2001) survey of BME organisations, found that some of the BME organisations had been operating for more than 10 years yet:

> *the organisations surveyed were worried about their ability to develop and about threats to their sustainability. Lack of easily accessible funding followed by lack of funding geared to the specific services provided were the two most commonly cited constraints to growth and development. Difficulty in securing core funding was a particular concern. Lack of official recognition was also perceived as an important constraint, particularly by informal organisations* (2001:3)

Funding difficulties are also experienced by statutory agencies (Mir et al, 2001).

The introduction of market forces in Local Authorities' social care provision resulted in their roles changing from providers to purchasers of social care services (Watters, 1996). The intention was to introduce a 'mixed economy of care' and reduce public spending by enabling local authorities to purchase social care from the voluntary and private sectors (Watters, 1996; Atkin, 1996; Scott and Russell, 2001; Locke et al, 2001).

This was considered to be a more efficient way of providing services (Watters, 1996), particularly as service users (consumers/customers) were to be consulted regarding planning (Locke et al, 2001) to develop user led services (Priestley, 1999a). Whilst this opened up avenues for these sectors to provide social care services, it was also based upon competitive bidding for contracts and service level agreements (Locke et al, 2001). Funding and criteria for assessment and provision of services also caused tension between the funding and assessing agencies and the providers.

Summary

A wide range of services were provided by the organisations that participated in this study, which illustrated the different services that intervene in the lives of disabled children and their families. Funding and criteria determined the services that were provided and where funding was received from various sources this could result in a tiered service, in which the needs of the service users might be similar but services are provided to those who meet the given criteria. Funding for core services could limit the ability of organisations to address both disability and ethnicity. Competitive bidding between services for funding could impede the multi-agency and multi-disciplinary work advocated for providing co-ordinated services for disabled children.

6.2 Specialist disability and BME Services

A major finding is that service providers focused either on disability or ethnicity but not both. This is because services for disabled people tended to focus on disability issues and services for BME communities tended to focus on ethnicity. Consequently, these services failed to acknowledge that South Asian disabled children and their carers experience both disability and racism and hence address their needs. Similarly Evan and Banton (2001), Flynn (2002), Flynn and Patel (2002), and Patel (2002) found that disability services concentrated on disability issues and BME organisations concentrated on ethnicity, resulting in BME disabled people 'falling between' these services (Evans and Banton, 2001).

However some of the disability services that were represented in this study also had projects that focused specially on BME communities, and/or had access to BME members of staff within their respective services. For example, three of the representatives (participants) were employed in (statutory and voluntary) specialist services that offered services to BME communities. Two organisations offered services to BME communities and only one organisation offered services that addressed both disability and ethnicity.

In this study, 'disability services' refers to those that specialise in disability issues (meeting the needs of disabled children and adults) and 'BME services' refers to those that focus on ethnicity (meeting the needs of BME and South Asian communities).

The findings reveal that both disability and BME services generally use a Universalist approach to service provision, which is aimed at providing services that are open to everyone (who meet the criteria of the service). The Green Paper – "Every Child Matters" uses the term 'Universal' services to refer to key services such as education, social care, health and childcare, and states that:

> *The Government would like to develop more and better universal services, open to all families as and when they need them* (Treasury Department, 2003:40)

In this study (other than when I refer and/or quote the Green Paper – Every Child Matters), my definition of the term Universal services is: services that are open to everyone (who meets the criteria), which implies that those people who use the services might be satisfied with these and/or that their needs will be met. However, this is not necessarily so, because the needs of certain groups (such as South Asian disabled children/young people and their parents) might not necessarily be taken into account at the outset, which could make services inaccessible to them. Therefore, although Universal services are open to everyone, they are designed to meet the needs of the majority and therefore are not necessarily accessible to everyone.

This results in differential treatment of those users whose access to services and needs are not the same as the majority.

6.2.1 BME services

Two community organisations (SP8 and SP17) provided services mainly to South Asian communities, which were open to everyone. Services that were especially for disabled people were not provided, *"But [they] were welcome, in the playgroups or other activities" SP8.*

SP17 explained that whilst they did not provide special services to disabled people they wanted to expand their services to disabled users in the future:

> *Yes and their carers, but there [are] no disabled projects, like in particular for disabled people. This is what we basically need to, want to improve on, to provide respite care for the children and the parents and the carers. And the obviously, not only respite care, but would be like other training, support and a particularly if there are health related issues...but that is something we need to do...(SP17)*

As mentioned in the previous section SP17 had been unsuccessful in a funding bid to improve their services to disabled users. However, SP17 has been awarded some funding to make the premises accessible, although additional funds were being sought to improve the toilets. Thus SP17 was gearing up to make their service physically accessible to disabled people in line with Part 3 – Access to Goods, Services and Facilities, of the Disability Discrimination Act 1995. However, accessible premises alone do not make services inclusive to disabled users because negative social attitudes to disability inhibit their participation in mainstream activities. For example, the South Asian parents' experiences (chapter 4) reveal that the majority did not use community centres and groups because of the community members' negative attitude towards disability and inaccessible environments. SP8 explained that disabled users are given special attention, to make sure that they are not excluded from mainstream activities, but are not given special services.

According to SP8:

> *No the activities are all the same and [if] they [disabled people] are there we give them special attention, one to one to try and make sure they don't miss out (SP8)*

Whilst it is commendable that SP8 and SP17 are attempting to include disabled users in mainstream activities, the social barriers such as society's attitude towards disability, which make disabled users' inclusion problematic, needs to be acknowledged as well. This is because of the general ignorance of non-disabled people in society and South Asian communities regarding disability, which could result in their feelings of curiosity, fear and reluctance to engage with disabled people and users. This might make disabled users feel different to non-disabled users and deter them from using mainstream activities, particularly where there is lack of disabled people using the services. Therefore, whilst special groups and activities for disabled people are not the answer to integration in mainstream activities, as a starting point these offer disabled people an avenue to meet and discuss common experiences. In addition, where disabled people's groups meet in mainstream organisations it can also assist with raising awareness about disability issues amongst the staff and other users. The staff within mainstream community centres and projects also need to be aware of the social barriers experienced by disabled people, including South Asian disabled people, which could prevent them from accessing community centres and mainstream activities. According to SP17 elements of appropriate services to South Asian disabled people include financial resources, sensitivity, an "*understanding of stigmas attached with parents/carers of disabled children*". BME services (including community organisations) need to raise both their own and their non-disabled users' awareness about the barriers (including stigma) that are experienced by South Asian disabled children and adults in their own communities and the wider society.

In general, disability services did not seem to recognise that South Asian disabled people were less likely to attend community centres and religious places that are frequented by most South Asian people because of the prejudice they experience within their own communities. Therefore information provision, through South Asian services and communities, is less likely to reach disabled people directly within these communities. Consequently, the strategy of informing South Asian disabled people through their communities, by word of mouth, rather than direct communication with them could be ineffective (discussed further in section 6.3).

6.2.2 Disability services

The focus of disability services upon disability issues (and a lack of focus regarding ethnicity) is illustrated by the barriers to services experienced by BME users that were identified by some of the representatives. Only 4 said that they did not think under use of their services by BME users was an issue for them (discussed in section 6.2.2.5). However, the majority of the representatives said that BME users did not use all their services because of the following reasons (discussed below):

- Services that were for everyone.
- Culturally appropriate services.
- Resources.
- Lack of statistical information.

6.2.2.1 Services that were for everyone

A Universalist approach to service provision, which is open to everyone, can result in different services to different people because everyone's access to services and needs is not the same (EOC, 2004). For example, South Asian disabled children and their carers might require services that meet their language needs and are culturally appropriate (Evans and Banton, 2001). A lack of awareness about this could result in services that do not meet their specific needs and thus can exclude them (Chamba and Ahmad, 2000).

For example, information about services provided only in English is inaccessible to those who require information in different languages and formats, without which they are likely to be less informed about the services that are available (Chamba and Ahmad, 2000; Mir et al, 2001). The South Asian parents' experiences (chapter 4) show that they encountered a lack of information in appropriate formats regarding their children's impairments and services, which restricted their ability to mediate between services and their children for appropriate services.

Translation and interpreting services

The provision of translated information and interpreters to South Asian users was ad hoc. Not all of the 22 organisations provided this and different approaches were used by 14 organisations that provided some sort of translated information and interpreting services. These included use of:

- Staff members who spoke one or more South Asian languages and interpreted when required.
- External interpreters if staff were unable to interpret.
- Language Line and other people who were willing to interpret.
- South Asian volunteers to translate and interpret for South Asian users.

Some organisations provided a poster about their service (which contained basic information) in a couple of South Asian languages, whilst others provided more information. Some organisations translated information according to need, which meant that translated information was made available upon request from the South Asian users for information in their preferred language and format. According to SP4 and SP13:

> *Because, although we are a rural community we do have a very mixed ethnic culture throughout the county, but we might just have one family or a particular culture in one area. So we have things translated at the specific need of that family and we use the translation service to do it. So that answers your question, it's not printed in that format in an Asian language but it is available (SP4)*

Well we could do that [translate information] if we are asked, but we have never really been approached about putting our information in a different language. Up until recently we had a very good XXX, who worked with the Muslim association and [who] would take information back to them and any families who had a disabled child and any families that we have are XX speakers, and if there is a need we would be able to do that, but that's not to say that it has been requested and we have a very active Muslim association in X and there are people within there who we know are happy to pass information on. It's not something we have had to do, but it is something we would do. And that's the same request if people needed enlarged typeface, but we don't produce, but if were asked we would (SP13)

However, to request translated information the users would need to be aware of the service, which creates a Catch 22 situation because a barrier to accessing services by South Asian parents with disabled children is their lack of knowledge about the services. According to SP11:

> *[If you] don't know services exist, ... how can you access something you don't know about? (SP11)*

According to some of the representatives, the reasons for not providing translated information were because they felt that the translated information might be academic, inappropriate and not used by the users. The South Asian user's literacy in their own languages could also not be assumed by the services. Qureshi et al (2000) found that some of the social workers in their study questioned the interpreters' objectivity and the accuracy of the interpretation, and they felt that training interpreters in the subject area could help. This is a moot point for South Asian staff members who have knowledge about the subject area, but might not be trained interpreters, yet they use (or are expected to use) their language skills for interpretation purposes in their organisations. This could result in misinterpretation of information and tension between their professional role (which might include advocacy) and the interpretation of dialogue, (which might not). This could also result in indigenous colleagues devaluing South Asian workers as co-workers in their services (BME staffing is discussed later).

The above shows that the provision of translated information and interpreting services, which are essential for communicating with South Asian users (and South Asian disabled users) who do not speak English, was unplanned. This suggests that in the majority of the services, information provision and communicating with South Asian users was not an integral part of service provision but an add on and therefore not budgeted for at the outset. A lack of information can affect South Asian non-disabled and disabled users and their carers' access to services.

Referrals

Access to services through referrals can also result in differential treatment of some service users because of their reliance upon services and professionals to refer them to the relevant services. The service providers used referrals to inform users and professionals about their respective services. However, whilst some service providers welcomed self-referrals from the users and also used 'word of mouth' strategies to encourage referrals (discussed in section 6.3), other organisations preferred referrals through statutory services. According to SP5:

> *As I say, it tends to be professional or they are working with the child, particularly as the referrals are usually channelled through recognised medical sources. That is the way we go. I prefer to think we have had some referrals for the local society obviously, who have worked within the Asian communities. But it does [tend] to be medical (SP5)*

Organisations that preferred referrals through professionals informed them about their services rather than the users. This has an impact upon the users' knowledge about the services that are available and how to access these. Referrals by professionals depend upon whether they are reactive or proactive and their knowledge about the services that are available (Twigg and Atkin, 1994). A reactive professional with a lack of knowledge of existing provision can result in a lack of referral to relevant services and, therefore, the user missing out on services that they might need (ibid).

For example, Flynn and Patel (2002) found a lack of networking between the statutory services, established voluntary sector and BME voluntary sector, with the consequence that BME community organisations were unaware about services such as short-breaks. They were therefore unable to inform their users and community members about short-break services and to refer them as appropriate.

Proactive professionals can enable intervention from a greater number of services. For example, the South Asian parents in this study (chapter 4) who had intervention from a wider range of services were better informed and supported than those who were not. However, South Asian users might not wish to be referred through statutory services such as Social Services, which might result in them abstaining from using services (Flynn, 2002). According to SP20 South Asian users are reluctant to be referred through Social Services: EM/South Asian families "*don't want to go through Social Services. Even now don't want to go through Social Services*". This could be because they prefer direct contact with service providers and possibly staff that they might have had previous contact with, and/or had heard about (i.e. through word of mouth), from other South Asian users. Consequently, the policy of referrals as an avenue to access services adopted by some organisations, has an impact upon the resources that South Asian parents with disabled children will have available to support their children.

6.2.2.2 Culturally appropriate services

In recent years, despite an attempt by statutory and some voluntary organisations to make their services appropriate to South Asian communities, they have failed to do so. This is generally because of the lack of commitment to budget for equal service provision for BME and South Asian users at the planning stage and lack of knowledge about these communities. Both of these aspects are required for culturally competent agencies that meet the needs of the service user. Other aspects required for a culturally competent agency include:

- Recognition of the social exclusion and barriers experienced by BME and South Asian service users.
- Knowledge about cultural practices and religious beliefs.
- Effective communication (meeting language and communication needs).
- Skilled and diverse workforce.
- Resources at the outset.
- Recording and monitoring use of services.

In this study the term culturally competent agencies refers to those agencies that consider the aspects mentioned above which are required to provide culturally appropriate services. Culturally appropriate services are those services (provided by the agency), which meet the needs of the individual such as communication, diet, understanding of cultural practices and religious belief and factors that result in social exclusion and under use of services.

Multi-culturalism as a response to deal with BME users still exists. For example, SP13 explained that services could be appropriate to Ethnic Minority and Asian disabled children in the following way:

> *Well, I think the same goes for all disabled children, as long as that service is acceptable and in terms of health, cultural, diet needs. All our play schemes have books and cooking utensils for wider cultures, quite often we learn to make sure, we are inspected by [the local authority] and so we have to follow their procedures, and that's the same for any school or nursery, and looking at culture and perhaps an ethnic minority group is very important to us. For example we may have vegetarians, we make sure that they are catered for. We also, obviously people may need to bring something along with them that is associated with their cultural xx and that's acceptable. We you know, we hope we do everything we can in the same way for any other child really. We do have toys that reflect* the cultures, *we look at other festivals we don't just look at Christmas, for example we will do stories that have got ethnic minority groups, in the same way we buy books that reflect wheelchair users. So it's something that's important to us. As I say, we hope we are welcoming everybody really, it's difficult to say, we try and encourage everybody and anyone can come in, it's a political issue really (SP13)*

According to SP7 visual images (of diverse groups of people) were displayed within the premises where they are based and they *"celebrate festivals"*. They also strive for a more representative staff but have not succeeded with this. Whilst this might make the premises welcoming and help to reduce the alienation that some BME users might experience, it is insufficient for achieving culturally appropriate services. This is because at the heart of culturally appropriate services is an acknowledgement by service providers that BME users experience racism in British society. This impacts upon their socio-economic position and access to service provision, which is designed for the majority. Consequently, both resources and knowledge about BME communities is required to make services culturally competent. For example, the knowledge that South Asian communities are heterogeneous – that there is cultural commonality between different South Asian groups but also differences. Also for example, providing Halal food for all South Asian non-vegetarian users could result in meeting the dietary needs of those who require Halal, but not of those whose beliefs might differ. Cultural, traditional and/or religious beliefs are interpreted at both the macro and micro levels. Thus it is important that service providers seek individual interpretation to provide culturally sensitive services, rather than relying on generalisation (Qureshi et al, 2000; Mir et al, 2001) such as 'they look after their own'. Greater awareness about the heterogeneity within Asian communities would go towards reducing the tendency of some service providers to hide behind a cloak of ignorance about South Asian cultures, which is often claimed to inhibit the provision of culturally appropriate services (ibid). According to SP5:

> *Obviously, we have to have an understanding of the background of the family. A number of Asian families or ethnic minority families, the extended families are responsible for the upbringing of the child more often than any other community. However, because of that they don't take up the nursery places and play groups in the same way, as a family who haven't got an extended family or unit family can't possibly use that source. The awareness of the...background and what is appropriate or inappropriate, we would like to work with both parents and sometimes that [is] not appropriate within the ethnic minority/Asian families. As I say, there is a high percentage of grandparents who do the caring role (SP5)*

However, SP3 acknowledged that there is a need to learn about BME/South Asian communities to provide appropriate services:

> *I think we are slowly getting better [at] engaging with all the cultures, ...for example, it's a continual learning process. But it's only in the last three years that we really understood that we needed to do something for wider learning (SP3)*

According SP8, ethnic minority and South Asian communities might not use services because:

> *...Other community centres they [ethnic minority and South Asian communities] don't take up because of language, maybe because no Asian workers are there, maybe they are not comfortable of going to find out if they can come or not, or very approachable (SP8)*

Mir et al (2000) found that the best examples of culturally sensitive services were from BME services. Similarly, Flynn and Patel (2002) found that BME organisations were meeting the needs of BME users, but not of BME disabled users. This was illustrated by the lack of use of BME organisations by disabled users, and therefore these organisations need to be sensitive to both cultural and disability issues. This is because BME disabled people experience both racism and disability (Evans and Banton, 2001; Hussain et al, 2002).

6.2.2.3 Resources

According to the majority of the service providers, funding, as discussed above, restricted the provision of services to BME (and BME disabled people). Staff representation is discussed later in the section.

6.2.2.4 Lack of statistical information

Monitoring of services was ad hoc, for example some organisations in this study monitored the user's age and/or disability, but not ethnicity. Consequently some of the representatives were unable to tell whether BME users used all their services because according to them statistical information was required to ascertain this.

Yet information about the background of the users was not obtained by all the organisations in this study, which created a Catch 22 situation. According to SP13:

> *We don't really monitor breakdown in terms of culture, we have to have a regular breakdown in age really. In terms of who is moving onto what service, so we don't necessarily look at how many Asian families or how many Italian families we've got (SP13)*

SP4 was unable to retrieve data although the use of their respective services was monitored, which made this an ineffective tool for service planning. According to SP4:

> *I wouldn't [be able to give breakdown] I'm afraid because I took up post XX and I initiated data gathering. We do have, I don't have it to hand, I could get access but it wouldn't show ethnic minority access as it's a fairly new computer system and it's not something on the referral form flagged up as something to be recorded. It's from now...really (SP4)*

However, the details (number, gender, disability, age and ethnicity) of the users and staff were not provided by all the organisations. The use of services by different groups of people can only be identified if it is monitored and recorded, and can be retrieved as required. This would help to ascertain who is using the service and their satisfaction with it (CRE, 2000). This would assist with improving services, particularly to those users who might not be using the service. The Commission for Racial Equality (CRE) (2000) argues that ethnic monitoring of staff and users would enable services to evaluate the effectiveness of their equal opportunity and race equality policies. It would also assist with identifying areas that need improving. The Race Relations (Amendment) Act 2000, places a general duty upon public authorities, which is enforceable, *"...to promote race equality and good race relations"* (CRE, 2003c:2). However, the general duty does not compel public authorities to monitor policy and service delivery. A lack of monitoring (and data) by services could make it difficult to show that they are meeting the *"...duty to eliminate unlawful racial discrimination, and promote equal opportunities and good race relations..."* (CRE, 2003c:3/4).

Ethnic monitoring (by default) as a result of the Race Relations (Amendment) Act 2000 should provide information about the services that are used by South Asian disabled and non-disabled users. Statistical information should also inform policy makers and planners about the extent of their inclusion and exclusion from mainstream and specialist services.

6.2.2.5 Under use of services not an issue

Four representatives, 3 of whom were statutory providers, said that BME people were using the full range of their services. According to SP4:

> *I think what makes them use the services is that they have a very definite and clear need. If you are deaf, you are deaf. If you are blind, you are blind and have a need for the services. I think it's services where ethnic minorities feel they should be able to cope or they don't want to bother people or they don't know how to access then where we find that there may be difficulty with them using them. But the children are identified by health visitors or in school and the parents are supported to access the services and I think that's what the difference is (SP4)*

Statutory services are obliged to provide services such as education, health and social services to those people who fit the remit of their statutory duties. For example, Local Education Authorities are obliged to provide education to all children (Education Act 1994) and for the children to attend. Thus education services, including specialist services to disabled children, might not be under used by South Asian parents and children because they are obliged to ensure that their children receive formal education, which for the majority is through state education. Those parents who have the resources can choose to have their children educated in fee-paying rather than state schools. However, the disabled children/young people in this study attended state education (mainstream and special) and some of them experienced a lack of understanding about their specific impairment and also their experience of social exclusion. South Asian parents of disabled children experience greater hardship than their indigenous counterparts (as found by Chamba et al, 1999) because they are likely to be employed in lower paid jobs and experience difficulty in accessing benefit entitlements.

They are therefore unlikely to be able to afford to pay fees for their disabled children's education. In the absence of an alternative, the South Asian disabled children/young people in this study had to use state provision and therefore they did not have a choice other than refusing to attend school. Consequently, statutory service providers such as specialist education services and social services might feel that South Asian communities do not under use their services. According to SP5:

> *I don't think I'd concur with that [under use of services by EM/South Asian users]. The fact that we go in schools, the facilities or support services are there (SP5)*

However, this does not mean that their services are culturally appropriate and are meeting the needs of South Asian disabled children and their families.

Only one organisation addressed both disability and ethnicity, (it provided services to disabled children and their carers) and felt that low take up of their services by this group was not an issue. This was because they *"seem to have the right approach..."* and use of services by BME communities reflected the make up of the local population. According to the representative from this organisation, the BME staff within the service communicated in one or more South Asian languages and had an implicit understanding of South Asian communities' cultural and traditional 'norms'. There was an understanding that South Asian users might have different priorities to the ones that the service was funded to address. Consequently, this organisation dealt with the priorities of the users that led them to address issues regarding disability. Home visits and outreach work, and the location of the service in the 'heart of the community' also assisted with making the service visible and accessible. The representatives in this study agreed that the location of services could encourage use of services.

According to SP8:

> *We are in walking distance and where we are based there is more Asian people in the area and there is also a school near by, other playgroups near by, town centre near by so we are quite central. We are quite well known to people in this community (SP8)*

According to SP2:

> *I'm wondering whether services need to be more based in community resources which would be used otherwise by ethnic minority groups, for example if we were to run a local based clinic in on the XX, I don't know whether anyone has tried that or if it would be acceptable, but where people naturally go within their own communities, I don't know (SP2)*

Summary

Services that are for everyone could exclude those users (i.e. South Asian non-disabled and disabled users) whose needs are different to the majority. Disability services focused on disability issues and BME services focused on ethnicity but not both, which resulted in BME disabled users "*falling*" between disability and BME services. This is because they experience both disability and racism and therefore addressing either one of the issues is insufficient in dealing with the barriers that they experience. There seemed to be lack of commitment, knowledge and funding to make services appropriate and accessible to BME/South Asian disabled users. Monitoring the use of services by BME users was inconsistent, which resulted in a lack of knowledge about their use of services. There was a general lack of activity regarding the Race Relations (Amendment) Act 2000, which places a duty on some public authorities to develop a race equality scheme.

6.3 Solutions

The majority of the representatives suggested a variety of ways in which their services could be inclusive to South Asian users (and disabled users and their carers), such as:

- Conducting home visits.
- Staff dedicated to the user such as a liaison worker, key worker, and/or ethnic minority worker.
- Promoting the service via the media, such as the local radio.
- Culturally competent agencies that recognise the social attitudes to disability within South Asian communities and the wider society, and South Asian users' socio-economic position in British society.
- Location of services.

However, some of the services were already using strategies (discussed below) such as (6.3.1) targeted information campaigns and outreach work, (6.3.2) media, and (6.3.3) BME staff to inform South Asian users about their services and to encourage use of their services.

6.3.1 Targeted campaigns and outreach work

Some of the organisations targeted information about their services to South Asian communities through religious places, community centres and groups that are frequented by these communities. This was because 'word of mouth' was felt to be an effective way of informing South Asian communities about services, which could increase take up of services. According to SP19:

> *Well, mainly it's road shows and surgeries. Information in their own environments, hospitals and doctors surgeries. Anywhere where people gather we will make available, maybe a dozen leaflets ...pop in the shop, or telephone or e-mail enquiry, it's really how we do things (SP19)*

Some of the services provided information at events such as information open days and mela (gathering) which often draw large numbers of South Asian people.

Outreach work, which included meeting people in their homes to inform them about services, provide advocacy, and support (in their home) was offered by some of the organisations. This helped with encouraging use of services by getting information to those people who are unlikely and unable to access this through conventional means. According to SP20, home visits were conducted to South Asian families with disabled children to build a trusting relationship, which included an increased use of their service. Whilst outreach work such as home visits can encourage take up of services, targeting information in community centres, groups, religious places and events might be less successful in getting information directly to South Asian disabled children and their families. SP8 concurs that *"...networking and outreach, rather than events"* are needed to increase take up of services. This is because South Asian disabled children and their families are less likely to attend community facilities and events because of negative attitudes towards disabled people and inaccessible environments as illustrated by the parents' experiences (chapter 4).

By conducting targeted information campaigns service providers seemed to rely on community members to pass on information to disabled children and their families that they might know of, which might increase take up of services. Consequently, services depended on indirect rather direct methods to inform disabled children and their families about services that could be relevant to them. This study reveals that (chapter 3, section 3.2.3.4) direct methods worked better than indirect methods to gain access to South Asian parents for their participation in this study.

6.3.2 Media

Some organisations used the media, such as local radio, the local newspaper and/or community newspapers. However, this is based on the assumption that disabled children and their families have access to these avenues for information. There is also an assumption about disabled children's and their families' literacy in their languages and their capacity to read community newspapers in their own languages.

Whilst information can be made more widely available about services through the media (radio and Internet), it might not necessarily be accessible to disabled children and their families, including South Asian disabled children and their families. In this study only one parent (Sharmila) mentioned use of the Internet to search for information regarding her son's impairment. Only two disabled young people (Rajan and Rajeev) mentioned use of the Internet. Hatton et al (2002) found that South Asian families with disabled children were least likely to use the Internet to access information.

Some organisations used the Internet to provide information about their services to both users and professionals. Blasiotti et al (2001) argue that The Wide World Web has made a wide range of research, academic, practice and commercial information regarding disability issues and other issues available at a local, national and international level to researchers, practitioners and disabled people. However, accessing information via the Internet requires some knowledge and access to relevant technology, which is not accessible to all disabled users and professionals. Therefore it could exclude those non-disabled and disabled people who do not have access to such a facility. This can curb the potential that some disabled people have to access a wide range of information, collectivise and engage in political activity to achieve social change and it can also be an obstacle. For example, Blasiotti et al (2001) found that non-profit organisations experienced difficulties in updating information on their Web sites, which meant that their potential users might not have the relevant information that they require.

Some disabled people (including South Asian disabled people and their carers) might not have the resources to purchase technology for their personal use and/or might be unable to access public resources such as Public Libraries, which might allow free access to the Internet.

This is because disabled people and South Asian disabled people experience greater levels of under-employment in the labour market (Barnes et al, 1999; Drake, 1999) and therefore are dependent on welfare services and benefits, which reduces their ability to purchase and access technology. Some disabled people's access to Public Libraries and Cyber-cafes could be inhibited because they require transport, as with some of the South Asian parents and their disabled children in this study. Internet access also needs to be both physically and technologically accessible to disabled children and adults. This is illustrated, in chapter 4, by Rajan (South Asian disabled young person) who revealed that he sometimes found the information on the Internet inaccessible because of the font size that was used to present the information.

Mel Read (Member of the European Parliament) argues that technology designers and manufacturers (computers and software packages) need to consider at the outset the accessibility of computer technology to disabled people. Failure to do this could result in technology being bought and used by a range of agencies such as employers, who might argue that the requirement of the job is the ability to use the technology, as it is because adaptation might be costly. This would exclude those disabled people who require adapted equipment and therefore technology should be accessible at the outset (Read, 2003). The Internet is important for disabled children/adults and their carers because it is an increasingly widely used method of communication, which all disabled children/adults and their carers should have access to. This is because the Internet would give opportunities to access information from a wider range of sources (local, regional, national, European and global) and to interact with a wider pool of people at a local and international level. It would also give disabled people opportunities to form and maintain friendships, and to collectivise with other disabled people at a local and global level.

6.3.3 BME staffing

BME users could be encouraged to use services by the employment of staff from these communities. This is because BME such as South Asian staff are likely to: communicate in one or more South Asian languages; have an implicit understanding of South Asian cultural and traditional norms, and have experience of racism in British society. According to SP18:

> *Because I have an ethnic background and cultural awareness, my nursing helps me give advice like xx and speak with the professionals to make sure that ....the services are comfortable (SP18)*

According to SP3:

> *I think a lot of it is [if] we employ from those cultures and communities to integrate and influence their cultures. I think a lot, I think the take up is [about] us learning to communicate more effectively and I think the link with charity and perception of what a charity is. I think we need to divorce community services from the charity side of perception (SP3)*

SP22 explained:

> *No. I don't necessarily think that we have the service that ethnic minority or Asian families want, I think that's the first thing. And I don't think we have enough ethnic minority and Asian workers to make people feel comfortable in their home (SP22)*

The presence of BME and South Asian staff also projects an image of the service as diverse (Flynn and Patel, 2002). SP20, SP18, and SP11, explained that since their employment (within their respected organisations) to work specifically with BME communities, the take up of their services by these communities had increased. However, SP20 explained that since the developmental work that she had conducted, which led to an increase in use of services by these communities, her role had been made generic. This was because of the increased demand for services and the change in the Service Level Agreement between the organisation and the funding body.

This resulted in all referrals being made through the funding agency, which assessed the user's need for the service and referred them to the organisation accordingly. Self-referrals were also re-directed to the funding agency, and consequently, there was a drop in use of the service by BME users. This could be because BME users might be apprehensive of coming into contact (through referrals) with statutory agencies such as Social Services (Qureshi et al, 2000). Inappropriate assessment criteria might also result in lower number of South Asian users qualifying for services.

In general, there is a lack of BME staff in disability services and where they are employed this is in low paid and low status jobs rather than decision making positions (Mir et al, 2001). Consequently there is a lack of role models for South Asian disabled children and their families. Mir et al (2001) argue that BME workers might be deterred from working with the disability services because of:

- Short-term employment.
- Few opportunities for career progression.
- Perceptions by indigenous colleagues that BME staff are 'trouble makers' and/or 'experts'.

Flynn (2002) argues that the lack of BME staff within services could result in those who are employed shouldering the responsibility of working with BME users. It could also make their position lonely and cause tension between themselves and their communities (Mir et al, 2001; Flynn, 2002). Rather than relying on BME staff, all professionals should comply with meeting their services' equal opportunity (and race equality) policy (Mir et al, 2001).

Summary

The representatives in this study were aware of barriers that BME non-disabled and disabled users experience in accessing service provision, and proposed solutions to address this. Despite this awareness, BME service users under used their services. Various strategies such as targeted information campaigns, outreach work, media and the Internet were used by the organisations to inform service users about their services. This has the potential to increase take up of services, however, it also has limitations because BME non-disabled and disabled users might not have access to these sources. BME workers were beneficial to services because they increased take up of services from BME communities, however, they might be reluctant to work in the disability field because they are often employed in low status and low paid jobs.

6.4 Models used by the services

The descriptions of the approaches that were used by the representatives for service delivery are grouped as follows:

- Person-client centred (child-centred).
- Social model of disability (including user-led and political approaches).
- Medical model of disability.

However, not all the representatives used the model approach to describe their service delivery. For example, 3 representatives said that they were unaware of the social and medical models, one was vaguely aware and another was familiar with these models. Two representatives said that they did not use any models apart from meeting the needs of the users. The services that used the person and/or child centred, social and medical models interpreted these widely.

SP2 explained that a person-centred approach was used in their service:

> *It's basically person-centred. From those categories it would be person-centred. We are trying to basically find what individuals need and if there is common thread we would for example 'I really need someone to read my letters to me' and we get a dozen people in [an] area wanting that then we would obviously recruit volunteers to carry out that sort of work (SP2)*

SP22, a social care provider, explained that:

> *The approach that we are trying to get to use [is] very much child centred underpinned by children first value base. And I think, my primary guide to setting up services is very much Social Justice Model and disabled children have the right to access activities and opportunities for development and their siblings and peers, and that's the model we're trying to get to if I'm being honest…And we have had some training around Social Justice, Social Justice model that underpins Social Model of Disabilities and we do want to support anything that supports the kids at home but we are a children's services and we are there to assess needs and then any service provision should come from the Assessment Group informed by the Social Model (SP22)*

SP22 was trying to espouse the child centred model and also felt that this was based on the Social Model. However, the use of assessments to provide services deemed necessary by the assessment group could place a greater weight on the professional's perception of the individual's needs that are assessed, rather than the individual's perception about their needs. Consequently, service provision is based upon assessed needs rather than the individual's opinion about what their needs are and how these should be met. This is illustrated by Mr Patel (chapter 4) who felt that his son (Rajan) should be informed about the services, aids and equipment that are available to him, so that he could choose what he thinks is relevant to him rather than accepting the support that is offered by services. However, services might be reluctant to offer choice because assessment criteria and subsequent services are generally driven by budgets, and therefore service provision is usually universal rather than individual.

As regards to the Social Model, SP22 appeared to be using the compliance approach, which according to Oliver (2004) is about service providers meeting statutory obligation. In this approach:

> *Service users often feel disgruntled because they do not think that services are being organised according to disabled people's needs or rights. It is the producers who interpret the laws, rules and regulations, often adopting a checklist, or task oriented approach, that simply satisfies basic standards and demonstrates little sense of commitment to wider service goals or to a partnership approach with disabled users (Oliver, 2004: 27)*

Thus the compliance approach does not meet the framework of the Social Model, which is about enabling disabled people's access to equal services, rights and responsibilities and thereby attaining citizenship (Oliver, 2004). Oliver (2004) recently conducted a review of the implementation of the Social Model by Birmingham City Council and identified the following 3 approaches:

- Humanitarian - services are provided because disabled people are viewed with pity, which applies to most traditional charities;
- Compliance - services meeting their minimum statutory obligations
- Citizenship - the rights of disabled people to access services equally, which meets the framework of the Social Model (this was not being met by services).

Oliver (2004) also states that the Social Model is a tool and thus does not provide ways, in which it could be implemented, resulting in a lack of changes. So whilst service providers might claim to espouse the Social Model, in practice the control of what and how services are provided to disabled people remain in the control of the professional. In the current study, the statutory providers were striving to adopt the principles of the Social Model but appeared to be constrained by the dominance of the individual model (of which the medical model is a sub-set) that has historically been used in service delivery. This could be because impairment is diagnosed by the medical profession, which is informed by the medical model, and has an impact upon the assessment of the individual's needs for intervention from specialist services.

For example, SP6 and SP21 explained that they tried to espouse the Social Model in the following ways:

> *I think we'd say we'd adhere to the social model; obviously we have to take into account medical information e.g. our policy for the deaf is bi-lingual policy, we definitely strive to adhere to the Social Model. If we are talking about the deaf it's about, if you are looking at the medical model it's always about there is something wrong with the kids hearing and so what we say we recognise BSL which is sign language and English and the child has the right to access whichever language they need. It's about giving the children access and support they need, it's not about, ultimately if the parent don't want the child to use a hearing aid e.g. because they want the child to have BSL and access to deaf culture we respect the choice of the parent. Our philosophy is to support both whatever hearing they've got and give them access to BSL. We give them access to deaf adults, give a positive role model, you might be deaf but you can achieve without negative terms. We use the term deaf and not hearing impaired gives a more positive, I know they don't do that in X. We say the child is deaf not hearing impaired as the deaf community find that term hearing impaired a very negative model, a very negative medical. So it's about how we make things accessible to the child instead of how we treat the child, but as I say we also work very hard to support the audiological side of things and provide equipment to support the visual side of things so it's not that we don't acknowledge medical support if it's there (SP6)*

According to SP21:

> *We try to work towards the Social Model, but there is some pressure from schools and parents [who] like the security ...of the medical. We try to work to the fact that whatever that special needs for the child are, how would it actually react on their education. What is the value of education and try and reduce the impact on that...we are looking to make more inclusion so the parents have a real choice of education they can choose for their children (SP21)*

The representatives who said that they used the medical model or both the medical and Social Model appeared to associate the medical model with health based provision such as assessments to ascertain aids and rehabilitation. There was a general lack of awareness that the medical model prevents the individual (because s/he is viewed as incapable) from making decisions regarding the management of impairment, which includes decisions about medical intervention, support and care services.

According to SP4:

> *...Thinking off the top of my head, we do use a sort of diagnostic model and a social model in that we look at things like self-esteem and that is very important in the holistic approach that we use with the child. All children are looked at holistically and within that the medical, social and sometimes rehabilitation style, especially with children who have had behavioural difficulties ...(SP4)*

The Social Model (including the user-led and political) was interpreted, by the voluntary organisations as providing flexible services to disabled users, which included one or more of the following to make the services accessible and relevant:

- No waiting lists for getting services.
- Dedicated staff to support families and their disabled children.
- Choice of services and meeting the needs identified by the user.
- Allowing the user to define themselves as disabled rather than imposing a definition.
- Providing information and advocacy so that disabled users were empowered to make informed choices.
- Partnership approach with other agencies to meet the users' needs.
- Self-referrals and referrals from other services/professionals.
- User involvement.

The above bullet points do not seem to reflect the framework of the Social Model, but it seems that the voluntary organisations were trying to reduce and/or eliminate barriers to services experienced by disabled people such as waiting lists, that could prevent access to timely and appropriate services. In the absence of a guide of how to implement the Social Model in practice there appeared to be some confusion about this (Oliver, 2004).

SP19 described the use of the Social Model in their services as:

> *We are more about empowerment. There is a route for advocacy, a more reliable [model] than the medical model, so we say here's the information to make the choices and if you get stuck then come and see us and we'll try to help you (SP19)*

SP15 explained that people who defined themselves as disabled used their service, rather than the service imposing a definition. Whilst self-definition might empower individuals to define themselves, it might also exclude them from using services that are funded for disabled people whose criteria might be based on a deficit model of need. For example, to qualify for services individuals might be required to define themselves as disabled and/or meet the definition stated in the DDA 1995. Subsequently, services are provided according to what disabled people can and cannot do in comparison to non-disabled people. Consequently, individuals who do not define themselves as disabled might not qualify for services that they might be entitled to and need. Therefore, individuals need to be aware of the implications of defining themselves using alternative models (Social Model) other than the medical model that is used by some services and funding organisations.

Regarding user involvement, some of the organisations explained that they had representatives from BME and/or disabled people on the management committee of the organisation. However, this does not necessarily mean that they are involved in decision-making and/or that their views are heard. This is because often there are few BME and disabled people as committee members (Drake, 1996) and due to their small numbers, and their general devalued position in society (as members of marginalised groups), they are likely to have little influence to enable organisational change. There might also be tension between the users' and the committee's goals for the organisation (Harris, 2001). For example, Drake (1996) argues that charities for disabled people have philanthropic and paternalistic roots and have historically been informed by the medical model.

Their role in achieving social and political change for disabled people continues to be restricted because of their funding relationship with the state. They inform and implement policy, which appeases disabled people's position in society but which does not give them control of the decision and policy-making mechanisms (such as charities) that have some control over their lives.

The voluntary organisations, whilst claiming to adopt the Social Model appeared to be using the humanitarian approach, in which:

> *...services are provided out of goodwill and the desire to help individuals and groups perceived as less fortunate. This means that the medical model is all-pervasive, with the professional expert in control of service provision, while the disabled person is regarded as a 'problem' (Oliver, 2004: 27)*

However, the voluntary organisations also attempted to reduce some of the barriers they felt were experienced by disabled people in accessing services and therefore, in a very small way, were trying to espouse the citizen approach in which the service users are enabled to access their rights and responsibilities. For example, information and advocacy provision could help to inform disabled people about their rights and how to exercise these. The elimination of waiting lists to their services and working with other agencies could help disabled people with accessing timely and co-ordinated services. Offering choice and user involvement could enable disabled people to 'have a say' in the services that they want and need. The voluntary organisations in these ways were attempting to work towards the Social Model, but also seemed to be constrained because of their use of the humanitarian approach and their lack of understanding of the Social Model, particularly in the absence of a guide to how it could be implemented in practice. For example, from a Social Model perspective all services should be inclusive to disabled people, and a lack of understanding of the Social Model results in a lack of meaningful changes for disabled people to access equal services and to attain citizenship.

During the last 20 years the disability movement has been instrumental in promoting the Social Model as an alternative explanation (to the individual model of which the medical model is a sub-set) of society's treatment of disabled people. The findings reveal that the majority of the statutory and voluntary service providers in this study had some awareness of the person/child centred models, and the Social and medical models, and that some organisations also claimed to use these models. The interpretation of the Social Model in practice was wide, but also seemed to be flawed. For example, there seemed to be a lack of awareness of the wider social barriers (other than physical barriers) that are experienced by disabled people to access service provision and their rights. This could be because "*There are no blueprints to guide its implementation and there is not a substantial body of experiences of how to do it"* (Oliver, 2004: 26). In the absence of a guide to how to implement the Social Model in practice, the service providers in this study seemed to apply it as they interpreted it at a local level and also in a way that did not seem to change service provision as intended by the Social Model. The impact of this on disabled people is that services might be accessible to disabled people due to compliance with disability legislation, but their treatment of disabled people in general might continue to exclude them, particularly in decision-making processes. Furthermore there seems to be no sanction imposed on service providers who claim to use the Social Model but do not implement it fully – that is make changes to services so that they are fully accessible. A guide explaining the Social Model and how it could be implemented (by sharing practice) might be useful for service providers to make their services inclusive to disabled people.

Summary

The person/child centred models, Social and medical Models were used by some the service providers. However, the interpretation and application of these models was broad, and the services that claimed to use the Social Model in practice appeared to be using the humanitarian and compliance approaches. The voluntary organisations, in a very small way, were trying to espouse the citizen approach (and thereby the Social Model) by reducing what they considered to be the barriers experienced by disabled people to accessing their services. Therefore, whilst some of the services were claiming to use the Social Model, in practice their services were not reflecting the changes that should occur to disabled people's access to services, their rights and citizenship.

6.5 Policy

The DDA 1995, particularly Part 3 (Goods, Services and Facilities) and Part 4 (SENDA 2001), provided the impetus for the majority of the providers to make their services accessible to disabled children and adults and not to treat them less favourably than non-disabled people due to disability (Swain et al, 2003).

Five representatives said that changes were being made to their services in light of the DDA 1995 (and amendments such as Part 4) that included physical changes, policy, planning and training of staff to make services accessible to disabled people. According to SP4:

> *There is strategic and planning changes in that I have asked all the services to allocate time rather than just hands-on time to develop strategies to address schools, governors meetings, etc., to discuss pre-planning for schools, know schools have a duty now, it can't just be reactive planning it has to be pro-active planning. Even if they don't have children with a disability they have to plan for that contingency. And so they are developing presentations and materials that will help in the school's development plans (SP4)*

Some of the disability services explained that they were already working with disabled people prior to the DDA 1995 and were involved in campaigning for disability legislation.

Therefore they had to make few changes because they were already meeting the requirements stipulated in the DDA 1995. According to SP3:

> *Yes. We'd already made the changes. We've been through an evolution of our policies and that has been quite severe (SP3)*

However, the representatives' responses suggested that there had been an impact upon their services because policies were being reviewed, and staff were being informed and trained regarding the DDA 1995. However, some of the representatives who were part of larger disability organisations and services were unclear about the implications of the DDA 1995. Although, they were informed about the changes that were occurring in the organisation through colleagues, who were selected to disseminate information about impending policy and disability legislation. Whilst there was activity to change services to meet the DDA 1995 (and subsequent amendments), in general, the representatives made no reference to the impact of legislation such as The Race Relations (Amendment) Act 2000. This requires local authorities (and those services involved in working in some public services) to produce a race equality scheme, which should set out how it plans to meet race equality in all aspects of their services (CRE, 2000). This suggests that the services were focussing on the disability discrimination that disabled users might experience, but not on other factors that compound their experience of discrimination due to ethnicity, age, class, gender, sexuality and religion. Consequently, the services seemed to consider disabled users as a homogenous group of people. However, the service providers might not have been forthcoming with information regarding the Race Relations (Amendment) Act 2000, possibly because a question regarding this legislation was not included in the questions, whereas one about the DDA 1995 was, which is an oversight on my part and resulted in a loss of information. However, as argued before, whilst legislation might ensure that services are accessible to disabled children and adults it is insufficient to make services inclusive to disabled children and their carers. This is because of the negative social attitudes towards disabled people, which also inhibit their participation in mainstream services and life.

Disability and BME service providers need to acknowledge that South Asian disabled children and adults experience multiple identities (Vernon, 1999; Ahmad et al, 2000) and that both disability and racism can inhibit their participation in mainstream life and activities.

The impact of the DDA 1995 and the Race Relations (Amendment) Act 2000 require evaluation, regarding the monitoring of the use of disability and BME services by BME disabled and non-disabled users. This should provide information about the effectiveness of legislation in compelling service providers to meet the needs of BME disabled users.

Summary

Disability and BME service providers were attempting to make their services accessible to disabled users in light of the DDA 1995 (and subsequent amendments and introductions). However societal attitudes towards disabled people require addressing if services are to be inclusive to disabled users (including South Asian disabled users). The impact of the Race Relations (Amendment) Act 2000 was not mentioned by the services, possibly because information about this was not specifically sought, which was a huge oversight, on my behalf, resulting in loss of valuable information

6.6 Discussion and conclusion

A sustained analysis of the analytical points raised in the previous sections is conducted in the following sub-sections:

(6.6.1)Service Provision

(6.6.2)To meet or not to meet the needs of South Asian disabled users?

6.6.1 Service provision

A finding is that some of the service providers that participated in this study felt that there was under use of services by South Asian communities despite the fact that some of the services did not monitor use of their services by these communities. According to SP2:

> *Very low. It has been of concern to a lot of people in the field of visual impairment for a long time. I know X X went to great lengths to try and develop specific services and they struggled. They employed Asian workers to carry out work and research and they didn't get very far. And to answer your question in my experience the take up is very low in services that operate outside the home (SP2)*

SP3 explained:

> *I would agree in comparison with indigenous population there is much lower than expected take up for a number of different reasons. Some because there is some very good culturally specific community groups providing support for example 'carers and xx' and other types of community organisations. We seem to find [that] the Asian culture are family orientated to the extended family than perhaps the indigenous population. Over-generalisation but it's just the feeling we get (SP3)*

Over a decade ago, Hill (1992) argued that BME disabled people experienced discrimination due to disability within their own communities and racism within the disability community. Unfortunately this continues to be reflected in services, which tend to focus on either disability or ethnicity but not both, resulting in BME disabled people and their families being discriminated against by both disability and BME service providers (Evans and Banton, 2001; Flynn, 2002; Flynn and Patel, 2002; Patel, 2002).

Common to both disability and BME services was the lack of commitment and knowledge to make services accessible to South Asian disabled children and their carers. This was demonstrated by the organisations providing services that were based on a 'one size fits all' approach (EOC, 2004). This meant that whilst the services might meet the needs of the majority, the needs of South Asian disabled users who do not 'fit into' the status quo are marginalised.

Consequently, the access of South Asian disabled children, adults and their carers to a wide range of services that are accessed by either indigenous disabled children, adults and/or South Asian children and adults was limited. The majority of the services addressed either disability or ethnicity, but not both which made the services inappropriate and/or inaccessible to South Asian disabled children, adults and their carers.

The fact that disability and ethnicity can be dealt with holistically was illustrated by one organisation in this study. In this organisation disability and ethnicity were the core business (it was not funded to provide services predominantly to BME communities but to 'all' disabled children/adults and their carers). Thus planning of culturally sensitive services to BME disabled people and their carers (and other disabled people and carers) was integral to service planning and delivery and not an add on, and suggests a way forward to all service providers to adopt a holistic approach to equality and aspects that contribute to the social exclusion experienced by groups of people such as South Asian disabled people.

Existing literature (Evans and Banton, 2001; Flynn and Patel, 2002) suggests that the provision of culturally appropriate services to BME disabled children and their carers needs the commitment of services to budget for meeting their needs at the planning stage. However, this does not seem to be happening in the services that participated in this study. This could be because the needs of BME communities might be considered to be extra to the needs of the majority and that they might be considered at fault for not assimilating into the host culture. It could also be that those people who make decisions about policy and planning initiatives are mainly white middle class men with limited implicit experience of disability and racism. This is demonstrated by the under-representation of BME non-disabled and disabled people in decision-making positions and their over-representation in lower status and lower paid jobs.

According to Modood the average earnings of ethnic minority men were less than white men and ethnic minority women's *"...weekly earnings were considerably lower than men's in all ethnic minority groups..."* (1998:61).

Regarding disability services, there is a lack of BME workers, particularly at management levels. However, there is an over-representation of some BME groups in particular areas, for example, African Caribbean workers in *"day care and residential but under-representation in community services"* (Mir et al, 2001: 53). BME staff could help to influence policy and planning of services that are culturally sensitive to BME users and depart knowledge about cultural issues within the services and staff teams (Mir et al, 2001). However, this is only possible if the skill and knowledge that BME workers possess is valued within staff teams and services. The lack of appreciation of the skills and knowledge of BME workers is demonstrated by their employment in mainly short-term projects and posts to work with BME communities. There is a general lack of recognition by service providers that most BME staff (in education, social care and health services) are qualified, trained and/or experienced to work with a wide range of people (other than BME communities). Moreover, short-term funded projects suggest that services view the meeting of needs of BME users as a short-term issue.

BME workers (as employees and users) engage with structures such as public authorities (statutory and voluntary services) that are institutionally racist (O'Neale, 2000). BME workers, because they are members of a marginalised group and are often in lower status positions have little clout to influence change in their service. This reflects the power that one group might have over another because of their dominant position in society, based on aspects such as ethnicity, age, class, disability, gender and sexuality. This power base is also reflected in an unequal funding relationship between the funding bodies, the established (white) voluntary sector and the BME voluntary sector. Although the starting point for the formation of the established voluntary sector and the BME voluntary sector is different (Institute of Race Relations, 1993), the issue they

have in common is that they emerged to meet needs that were not being met by statutory providers, or to supplement statutory service provision (ibid). However access to funds, particularly through the contract culture that emerged during the Thatcher era (1980s) in an attempt to retrench the welfare state, (Harris et al, 2001) continues to be unequal between the established voluntary (white) and BME voluntary sector. This could be because in comparison to the established voluntary sector, the BME voluntary sector lacks fundraising capacity (Ahmad, 1998b; BTEG, 2003) and knowledge regarding governance. Furthermore there is a lack of support with these issues from statutory funding bodies (Joseph Rowntree Foundation, 2002). According to the Joseph Rowntree Foundation:

> *Organisations and groups with the right skills, experience, confidence and knowledge, find it easier to bid for contracts and work with local authorities on their own terms (1997:1)*

The position of the BME voluntary sector to meet the specific needs of their communities is also threatened by the established voluntary sector whose services have been inaccessible to BME communities. However, in recent years, the established voluntary sector has attempted to make their services accessible to BME users, generally through external funds that are targeted at BME communities, rather than meeting the needs of BME users from their own funds. For example, the RNIB secured funding, from the National Lotteries Board, to develop a 3-year project to explore the needs of South Asian parents and carers with visually disabled children (my experience of working with the RNIB Asian Families Project). This means that the BME organisations that have the infrastructure to ascertain needs and develop services in their communities are sidelined and are often expected, by established organisations such as the RNIB, to assist with accessing BME communities, even if there is a lack of a networking relationship between them. There is also a lack of recognition by established organisations that BME groups are often vying with them for the same funds and the same users, which is likely to cause tension between them. This has implications for the multi-agency working that is advocated for providing co-ordinated services to disabled children and their families.

Consequently a more effective use of such funds is a partnership between the established voluntary sector and BME voluntary sector to explore needs and develop services that are inclusive to disabled members of their communities.

6.6.2 To meet or not to meet the needs of South Asian disabled users?

A finding is that the services that participated in this study failed to provide an appropriate information service to South Asian users, including South Asian disabled users and their carers. This was despite the fact that the service providers were aware of the barriers to participation and also aware of some of the solutions to making access easier for South Asian disabled children and their carers. For example, the basic knowledge that information about services is vital for users to know what services are available to access, was not acted upon in a consistent way for South Asian non-disabled and disabled users, whose access to information might differ to the majority. The literature (Shah, 1995; Drake, 1999; Chamba and Ahmad, 2000; Flynn, 2002,) highlights the point that a major barrier experienced by South Asian parents with disabled children, in accessing services, is the lack of information regarding their children's impairments and services. This is because of the lack of information that is available in appropriate languages (South Asian languages) and formats (translation information, interpreters) regarding the services and benefits that are available and how to access these. Co-ordinated, consistent and appropriate information and communication services to BME communities could assist them to make informed choices about the services that are available, which would solve a problem with accessing appropriate information. However, another barrier that needs addressing is making services appropriate so that they meet BME users' needs, which could be achieved by making organisations culturally competent and also by acknowledging the existence of institutional racism and implementing strategies to address this at a local level.

In this study, the provision of accessible information to South Asian users depended upon the professionals' perception of the quality of the translation

and interpretation, and the actual need for this by South Asian users, thus undermining South Asian workers' 'expertise', which indigenous professionals might not have. Other aspects that could prevent the provision of translated information and interpreting services could be the service providers' perception that it is South Asian users' 'fault' that they require information in formats other than English, and that to access services they should learn English, and/or in time they might do so. It could also be that South Asian disabled children, adults and their carers might be considered to be a minority within a minority and thus making information accessible to them might be perceived as diverting resources from providing services that could be accessed by the majority (Drake, 1999). This could also be perceived as giving South Asian users better treatment, which could be unfair to the majority. However, these aspects need to be considered in the context of South Asian communities and particularly South Asian families with disabled children's socio-economic position in British society, in which they experience institutional racism. For example, Chamba and Ahmad (2000) argue that legislative and policy initiatives are applied through welfare services and thus rather than enabling citizenship of everyone, welfare services inhibit the citizenship of BME people because their access to welfare services is considered illegitimate. Universal services tend to meet the needs of the majority, which could result in the marginalisation of meeting the specific needs (such as diet, language) of groups such as BME communities, but they might have to access these services because there is no alternative. Chamba et al (1999) found that South Asian families with disabled children experience greater disadvantage and hardship than their white counterparts. They are more likely to be unemployed and rely on welfare services and benefits (similar to other families with disabled children) (Beresford, 1994; Katbamna et al, 1998). However, their access to welfare services and benefits is more difficult because of a lack of knowledge about the services that are available and how to access these. They are also likely to wait longer to receive services and receive a lesser amount in benefits than their white counterparts (Mir et al, 2001).

This has an impact on South Asian parents' ability to mediate for services for their disabled children and to support them (as discussed in chapter 4).

Whilst a wide range of statutory, voluntary and community services are available, these are not necessarily accessible and appropriate to South Asian disabled children and their carers. Consequently, they might continue to struggle despite a range of services that are available (Mir et al, 2001). However, some South Asian non-disabled and disabled users might refrain from using services that are inaccessible and culturally inappropriate, such as short-break services, which they have a choice to use if they qualify (Flynn, 2002; Flynn and Patel, 2002).

The organisations, in this study, used strategies to encourage use of their services that included employment of BME staff and targeted information to South Asian organisations and communities. There was a general lack of recognition that South Asian disabled children and their carers are often inhibited in using their own community organisations because of negative social attitudes towards disabled people and inaccessible environments. There was also an assumption that information might be passed on to South Asian disabled users and their carers and consequently, the services passed the responsibility of informing South Asian disabled people about their services on to the community members and organisations. According to SP2:

> *I have approached, when I worked in X, the religious leaders and although I was well received and left literature and tapes, and was assured that we do know of people who have [...] difficulties, and I made it clear that people didn't have to be registered, but no referrals came through. I can only assume my approach was wrong (SP2)*

The community organisations, the South Asian community and South Asian users themselves could be 'blamed' if the services are not used. This is because the services could claim that there was a lack of interest in their services despite targeting information to South Asian communities and users.

Thus services get away with using indirect methods rather than direct methods of information provision to South Asian disabled people and their carers. Indirect methods of communication also perpetuate the dependency of South Asian disabled people on other members (usually non-disabled) of their community to access information that is relevant to them.

The DDA 1995 was instrumental in raising awareness about the exclusion of disabled children and adults in mainstream, disability and BME services. This was illustrated by the physical and policy changes that were taking place in the majority of the organisations, including those which claimed to be at the forefront of campaigning for disability legislation. However, as argued before, making services accessible due to a legislative push is a start but it is not enough to make services inclusive to disabled people. This is because of the negative social attitudes towards disabled people, which prevent them from accessing services, which also need to be addressed. The change in attitude in society regarding disabled people should complement legislation to address the institutional character of disability and racism. This would demonstrate a political commitment for equality and social inclusion of excluded groups such as disabled people and BME people. It seems that at present there is disability legislation but a lack of commitment (resources) to raise awareness within society about the rights of disabled people (and the mechanisms that socially exclude them), through community development and community education (such as community arts programmes, drama and theatre workshops).

Whilst the majority of the services were aware of the person and child centred model, Social Model and the medical model, the interpretation of these models was wide. This resulted in the majority associating the medical model with health based needs and the Social Model with meeting social care needs, although the voluntary organisations addressed barriers to their services by making access to their services easier.

However, the Social Model's concept of enabling disabled children and adults to have control over their lives and to be included in mainstream services and life was generally not reflected by the services. This means that whilst services claimed to use the Social Model, in practice the social change that was claimed to occur in the lives of disabled people with the use of this concept was not generally occurring because of its wide (and often inaccurate) interpretation. This could be because services and professionals were unclear about how to apply this concept in their practice, in which the views of disabled children and adults should be central to the services that they received and therefore central in service planning and delivery. This suggests that disabled children and adults should be involved in decision-making at all levels, yet they might be construed by service providers and professionals as being incapable of doing so. Service providers and professionals might also feel threatened concerning the sharing and/or relinquishing of their power in the decision-making process.

Whilst there was awareness and activity in the organisations regarding the DDA 1995, the same could not be said about the Race Relations (Amendment) Act 2000. This was not mentioned by the organisations, perhaps because it was not raised by myself during the interviews, despite the fact that addressing both racism and disability is important to South Asian disabled service users. The Race Relations (Amendment) Act 2000 is important for service providers because it can enforce public authorities (that are not exempted) to develop a race equality scheme and to meet this (CRE, 2000). Whilst this does not make monitoring the ethnicity of the users of the services compulsory, it might compel services to develop consistent methods of collecting and recording information about their users and employees that include their ethnicity. The literature (Mir et al, 2001; Flynn, 2002; Flynn and Patel, 2002) and the findings in this study reveal that at present the monitoring of use of services and employees, by most organisations (statutory, voluntary and community), is inconsistent and that ethnicity is not always recorded. This makes planning and developing services that are inclusive and accessible to BME non-disabled and disabled users difficult.

In conclusion

Services that are for everyone could exclude South Asian disabled and non-disabled users, whose needs are different to the majority of the users because they are designed to meet the needs of the majority. Funding criteria can result in an unequal and tiered service provision in which the needs of some users are met because they meet the criteria, whilst those of other users are not.

Competitive bidding for funds could impede multi-agency and multi-disciplinary work that is advocated for providing co-ordinated services to all disabled children and their families. This is because of the tension that is caused between agencies that are bidding for funds from the same pot of money, and often providing services to the same users (South Asian non-disabled and disabled users). Providing services in the face of the funding difficulties that are experienced by both disability and BME services could result in the needs of South Asian disabled users being unmet by these services. This is despite anti-discrimination legislation such as the DDA 1995, Race Relations Act 1976 and Race Relations (Amendment) Act 2000) that require service providers not to discriminate against users because of disability and/or ethnicity.

This chapter concludes the presentation of findings and analysis regarding the experiences of the three groups of participants. In the next chapter, I present and discuss the major contribution this study makes, propose recommendations and conclude this study.

CHAPTER 7 DISCUSSION AND CONCLUSION

In this concluding chapter, I demonstrate the original contribution that this research makes to the field and propose recommendations and future work. This chapter is structured as follows:

(7.1) Contribution to the field

(7.2) Recommendations and future work

(7.3) Conclusion

7.1 Contribution to the field

This study contributes to Existing knowledge (7.1.1), Practice (7.1.2) and Policy (7.1.3), discussed below.

7.1.1 Existing knowledge

> *Disabled children and their families are often excluded from participation in ordinary activities and experiences. All services should be accessible to disabled children and their families, and services should support their contribution to everyday life (Audit Commission, 2003:24)*

A major contribution that this study makes is that of making the experiences of South Asian disabled young people and their parents visible and heard. This study also confirms and complements existing knowledge regarding the social exclusion that disabled children and their parents experience from mainstream life and activities (as illustrated by the above quote), which for South Asian disabled children/young people and their parents is compounded by racism.

7.1.1.1 Models of interaction and the awareness of the Social Model

The Social Model was used to examine the experiences of South Asian disabled children/young people and their parents because it provides a useful framework to explain society's treatment of disabled people. This is because the Social Model identifies the social barriers that inhibit disabled people's participation in mainstream life and activities. Consequently, this framework helped to suggest solutions that are based upon re-structuring society's

treatment of the disabled individual rather than adjusting the individual (Oliver, 1998). The appropriateness of the Social Model to understanding the treatment of South Asian disabled people is discussed in chapter 1, section 1.1.2.4 and also below.

The South Asian disabled children/young people and their parents, in this study, were generally unaware of the Social Model. This was mainly because their perception of disability was influenced by the responses of individuals in society and the professional's treatment of disabled children and their families, which applied the individual model (and medical model) (defined in chapter 1). The parents were also influenced by the prevailing ideology in society that views disability as a 'defect' resulting in conceptual barriers in viewing disability in a positive way. Consequently, the parents' interaction with their disabled children reflected this model, which was also internalised by the disabled children/young people.

The disability movement has only been able to use the Social Model to successfully raise awareness of the social exclusion that disabled people experience at a political, policy and service provider level. Whilst, there has also been some impact at a societal level, particularly amongst those who work with disabled people through employment and voluntary work, the parents of disabled children are less likely to be aware of the Social Model. This is because whilst the majority of the public might be unaware of the Social and individual models, their approach to disabled people demonstrates 'otherness'. For example the South Asian disabled children/young people and their parents were made to feel different by being stared at and unsupported by non-disabled people in their own community groups, local neighbourhood and the wider society. This was compounded by inaccessible buildings and services, which did not take into account their needs because they were designed for the majority, resulting in isolation that was externally and self-imposed.

For example, if a disabled person is unable to manage stairs then it is their 'problem' rather than the building being inaccessible and designed for non-disabled people – the individual is at 'fault'. Thus the 'otherness' that disabled people and their carers experience is associated with the individual model of disability. A CSR approach obliges researchers to take account of all forms of oppression and not just focus upon one, for example, the South Asian disabled younger people and their parents experience structural oppression, some of which is racially based and some of which is best described by the Social Model.

The South Asian parents were reluctant to use their own community groups because they experienced curiosity from non-disabled members, a lack of support with looking after the disabled children, and inaccessible venues. This suggests that the community groups catered for the needs of the majority of the community members, but not necessarily those of disabled members in the shape of accessibility and support. This could inhibit their participation in ceremonies, gatherings and being able to socialise with their non-disabled and disabled peers in their own communities and exclude them from socialisation, into group norms, that occur at a community group level. This reinforces their invisibility in their own community groups and isolates them from activities that are enjoyed by their non-disabled peers. This means that South Asian disabled children/young people and their parents could be compelled to use specialist services for disabled children and adults (leisure, health, social care and education) which reinforces the message that they are different to the majority in their own communities and the wider society. This also suggests that generally the members who are involved in decision-making within community groups might lack an awareness of anti-discrimination legislation and/or the push to implement this internally and externally. For example, smaller community groups might not receive funding from statutory bodies and therefore are not obliged to adopt their equal opportunity policies.

Smaller community groups are also unlikely to be challenged by disabled members and their carers because of their possible lack of awareness regarding disability legislation (evidenced in this study) and their devalued position within their own communities and the wider society. This could result in a lack of their engagement in the disability movement's quest to reconstruct society's treatment of disability and therefore to restructure their social position in society (from devalued to valued members in society).

Morris argues (1998a/b) that the failure to protect disabled children from abuse is because of their devalued position in society, which is reflected by the lack of mechanisms to:

- Educate disabled children to recognise abuse.
- Support them to disclose abuse.
- Address the abuse that they experience.

In this study the supervision of their disabled children increased the parents' caring responsibilities. However, by supervising their disabled children the parents ensured the safety of their disabled children from their potential vulnerability to abuse. Supervision also meant the disabled children spent their time in supervised (adult) company. For the South Asian disabled children in this study, who attended special schools and activities, their access to opportunities to socialise with a wider group of peers could be limited because they spent their educational and social time in supervised company. This means that these disabled young people miss out on the social and leisure opportunities that their non-disabled peers have to enhance their social and personal skills because of disabling environments. They also miss out on attending mainstream youth services (including those specifically for BME and South Asian young people), which provide advocacy and information regarding issues that affect young people such as sex and sexuality (safer sex), bullying, employment and social exclusion (DfES, 2002b), because they are often inaccessible to disabled/South Asian disabled young people.

A study by the Disability Rights Commission (DRC) found that:

> *32% of young disabled people said that they were not able to join in with most of the things their friends did such as playing sport, going to pubs and clubs, going on holiday and going to concerts and the cinema. Many respondents who had difficulty accessing leisure services said they would like to do so if better facilities were provided (2003:3)*

Special education and training programmes are often considered as inferior (Tomlinson and Colquhoun, 1995) and therefore attendance to these could also reduce the employability of South Asian disabled children/young people. This is compounded by the lower expectations by adults (teachers and parents) of disabled children/young people's abilities and the lack of support to achieve their potential to contribute to the economy, and social and family life. For example, the South Asian parents of the disabled children who attended special schools and/or colleges were happy for their disabled children to be taught social and life skills, rather than academic subjects, and had limited aspirations for their children to engage in employment and family life. This contrasted with the South Asian disabled children/young people's future aspirations, which included higher education, employment and travel, to which most young people aspire.

Disabled people are also likely to be denied access to information and opportunities to engage in sex, marriage, and parenthood. This is because of the general perception in society that disabled people are asexual (Middleton, 1999), their parenthood might result in an increase in disabled children (Jurkowski and Amado, 1993; Fairbairn et al, 1995; McCarthy, 1999) and/or they might lack an understanding about what is involved when engaging in sex and/or marriage.

In Gregory et al's (2001) study, the disabled young people said that:

> *...the attitude of non-disabled people was the single most significant barrier to exploring sex, sexuality and relationships* (2001:12)

In this study, the South Asian parents of disabled children with complex needs felt that their disabled children might be unable to comprehend the concept of marriage because they themselves required support. Consequently, these South Asian disabled children were likely to be denied access to encounters that could result in marriage in contrast to their non-disabled siblings and peers and therefore were treated differently.

That South Asian disabled children/young people are seen as different to the majority is also confirmed by diagnosis that defines them as 'defective'. This is re-iterated by a range of specialist services through assessments, which confirm that the child is 'defective' and requires correction and/or rehabilitation to be like non-disabled people. In the absence of prior experience of disability and a lack of awareness of the Social Model the South Asian parents believed the professionals' view that their children are 'defective', and require the kind of attention described above. This is confirmed by the South Asian parents' quest for treatment and cure for their children's impairments, and the hope that their children would participate in life and activities like their non-disabled peers (discussed in chapter 4). This desire was internalised by the South Asian disabled children/young people (such as Rajan and Rajeev) who also hoped for a cure for their specific impairments (discussed in chapter 5). This could be because they experienced social exclusion from mainstream life and activities, which their non-disabled peers did not experience. This indicates that the individual (and medical) model determined the lives of the South Asian disabled young people and their parents because of the treatment of disabled people by individuals within society and by service providers.

Service provision - models of interaction

The findings reveal that service providers claimed to use the Social Model, the medical and/or the person-centered models. However, there was a wide and inaccurate interpretation of the Social and medical models and in practice the service providers appeared to be using the humanitarian and compliance approaches. The service providers seemed to associate the Social Model with social care (rehabilitation) needs and the medical model with health needs. This means that there was a lack of understanding from a Social Model perspective that:

- The medical model (a sub-set of the individual model) focuses upon the individual's impairment as a limitation to their ability to participate in mainstream life and activities and therefore it is the individual that requires adjusting (through medical intervention and/or rehabilitation).
- The Social Model focuses on the social barriers (the way society is designed to meet the needs of the majority at the exclusion of disabled people) that prevent the disabled individual's participation in mainstream life and activities. Therefore the social barriers that are experienced by disabled people need adjusting.

As a result, the service providers' awareness of the Social Model did not necessarily result in disabled people and/or BME people's involvement in decision-making processes and taking control of decisions that affected their lives. Although, disabled people and/or BME people were represented on the management boards of some of the services, it does not necessarily mean that these services met their needs. This could be because these groups have little power (due to their devalued position in society) to make their voices heard amongst a group of people who represent the majority. The power structure within society is reflected in the management of some organisations, according to Sharma and Wilson:

> *...even organisations that have gone through changes continue to reflect the power structures which exist in society as a whole. Where disabled people have begun to be taken on in management or middle-management posts they are white, middleclass and usually have more socially acceptable or hidden disabilities (1992:7)*

Some voluntary organisations in small ways were trying to espouse the citizen approach and thereby the Social Model. For example, by improving disabled people's access to their services by reducing barriers such as waiting lists and allowing disabled people to define themselves rather than the agency defining them, which could be empowering. However, this does not mean that disabled and BME people are involved in decision-making processes and choosing services that they require. In order to do this they need access to services, information and advocacy to make informed choices and challenge decisions that do not meet their needs. For example, the South Asian parents in this study were informed at the outset about the research purpose, process, and their involvement during the various stages. They were provided with information about services (such as, social service department, Parent Partnership and voluntary groups) and contact was maintained (usually by telephone) with the parents during the research to inform them about the progress and to seek their opinions to inform various stages of the research. For example, the data collection process, and planning of the fun morning and the group interview with the parents (chapter 3, section, 3.2.4.2). The parents valued being involved in the research, which was demonstrated by their willingness to:

- Participate in the interviews.
- Allow access to their disabled children, and their participation if they wished.
- Offer their views regarding the various aspects of the research.

Consequently, the parents were a reference group for this study and were involved in the design of this study. Regarding service provision to South Asian disabled children and their parents, a significant finding (chapter 4, and 6) was that specialist disability and BME service providers concentrate on disability and ethnicity respectively but not both.

Hence a continued failure of these services to meet the needs of South Asian disabled children/young people and their parents, who experience both disability and racism. This is illustrated by their lack of access to information, advocacy and support to access services, and legitimate forums to discuss their concerns, which is discussed next.

Disability or ethnicity – lack of access to information, advocacy, support and legitimate forums

A 'one size fits all' approach was used by disability and BME service providers to provide services that were meant for everyone. This means that those people such as South Asian disabled children/young people and their parents' whose needs might not 'fit' with the majority are marginalised from accessing services that are accessed by their indigenous and/or non-disabled peers. Whilst, BME service providers provided culturally appropriate services to South Asian communities, they were less likely to be geared to meet the needs of disabled members of their community and their carers. This is evidenced by the under use of BME services by the South Asian disabled children and their parents in this study (discussed in chapter 6). BME service providers (like disability service providers) were making their services accessible in line with the DDA 1995, and claimed to include disabled people in mainstream services rather than providing special services. They did not however seem to be addressing, through raising awareness, the societal attitudes towards disability (curiosity, fear, abuse, lack of support), which also prevent South Asian disabled children, adults, and their carers from using community centres and groups. This means that the latter lack access to:

- Information and advocacy regarding a range of services, although BME and South Asian workers would need awareness of disability legislation, policy and barriers that are experienced by disabled people.
- Opportunities to meet with their peers to share concerns regarding experiences of racism in a safer environment.

- Opportunities to meet with their disabled peers (because of under use by them) to share concerns and represent their needs and views for appropriate services.
- Opportunities to engage in activities that are culturally appropriate and sensitive to disability issues.

The lack of access to BME services means that the South Asian parents' and their disabled children's invisibility is reinforced and denies them the opportunity to present their views through these services. It also means that they are unable to raise the awareness of non-disabled members about disability discrimination, their rights to access services and the barriers they experience because of disability. They are also unsupported and marginalised within their own community groups and by BME service providers, which refutes the view that is held by most service providers that South Asian people are 'supported within their own communities' (CIO, 1987; Shah, 1995; Qureshi et al, 2000).

Regarding disability service providers, a key finding is that they were aware of the barriers that inhibited South Asian users from accessing their services and solutions that could address this. However, their attempts to increase use of services by South Asian users were hampered by a lack of commitment and knowledge about South Asian disabled children's and their carers' experiences. For example, information provision seemed to be uncoordinated and inconsistent, and there seemed to be a reluctance to provide information (at the outset) that was in accessible formats to South Asian users who required information in languages other than English and formats other than print. This was because of concerns regarding South Asian users' literacy in their own languages (audio recordings could address this) and the accuracy of the translation (similar fears abounded about interpretation). Service providers were also unsure whether translated material was actually used by South Asian users. Consequently, some service providers made translated material and interpreting services available upon request.

However, the service user would need to know about the service in the first place to do so, which was unlikely for the South Asian parents in this study. This is because of a lack of access to information about the services that are available. This restricted their ability to advocate for appropriate services for their disabled children and also resulted in additional pressure to support their children, despite the availability of services.

Some services used information campaigns targeted at places congregated by South Asian communities (such as community centres, groups, religious places and community events). While these are effective at informing community members about services, they do not however necessarily inform South Asian disabled members, because they are less likely to congregate with other community members because of negative social attitudes and inaccessible environments, as evidenced by this study. This means that service providers relied on the 'good will' of non-disabled community members to pass on information to disabled members in their community. This could reinforce disabled people's dependency upon non-disabled community members and carers to pass on information. It could also reduce the disabled individual's ability to choose the information that they perceive as relevant. Consequently, targeted information campaigns could result in indirect communication, which is less effective than direct communication with South Asian disabled children, adults and their carers.

This study reveals that direct communication such as outreach work (face to face communication) with South Asian parents is more effective in informing them about services. This is because it allows information to be explained to the parents and trust to be built, which increases use of services. A similar approach was used in the semi-structured interviews with the South Asian parents in this study, whereby the parents were informed about services and their possible relevance to them (as required). This raised the parents' awareness about services and how to access them.

For example, Naseem Banu accessed services from a social worker (chapter 4), which illustrates how direct communication (outreach work) could result in advocacy, which South Asian parents usually do not receive from BME and disability service providers because of the disincentives to participate in these services.

Outreach work also encourages use of services and groups. For example, the South Asian parents attended the group interview that was organised during this study. This meeting provided the South Asian parents with a legitimate forum to find out about disabled children's services (in their local authority) and to express their views to a manager of disabled children's services (within one of six local authorities), who was invited for this purpose. They also found out about the DDA 1995 and SENDA 2001, of which they were unaware. This reveals that the South Asian disabled young people and their parents (in this study) were unaware of legislation and policy initiatives that directly affect them and consequently were unaware of their rights. This is despite the attendance of the majority of the South Asian parents (mainly women) at support groups, which they found both informative and empowering. The organisation that ran this support group claimed to provide updated information as relevant, (my conversation with the manager). Despite this, the South Asian parents were unaware of disability legislation, which is relevant to them and their disabled children. This suggests that whilst some support groups offer South Asian parents an opportunity to share their experiences, concerns, information and build their self-esteem, they are not necessarily informative about legislation, which is essential to ascertain rights and access to services for disabled children.

Referrals to services also hampered South Asian disabled children/young people and their parents' direct access to services. This is because some organisations preferred referral by other professionals rather than self-referrals, which could result in a delay in accessing services.

It could also mean a reliance on the professional's knowledge of existing services (Atkin and Rollings, 1996), which could result in a lack of provision if the professional is unaware of them.

Funding and criteria affected both BME and disability service providers, which restricted their ability to develop services beyond those that they were funded to provide. Evans and Banton (2001) argue that funding restricts organisations that focus on either disability and/or ethnicity from being able to develop their services to consider both. However, an unequal funding relationship between the established voluntary and BME voluntary groups could impede the latter's ability to develop long-term initiatives (Ahmad et al, 1998b). Restricted funding also led to the voluntary and community groups seeking funding from various sources with different criteria, which resulted in a two-tiered service provision. This meant that the needs of those service users who fitted the criteria (i.e. age, geographical area) were met, although all service users might have a similar or greater need for the service.

Summary

Whilst there is some awareness of the Social Model within service provision it has not resulted in the inclusion of disabled people in mainstream life and activities. The awareness of the Social Model as an alternative to the individual model has also not filtered down to BME communities, which has resulted in the continued exclusion of BME disabled people and their carers within their own communities and the wider society. BME and disability service providers focused on ethnicity and/or disability issues and not both, which meant that the needs of BME disabled people arising out of racism and disability were not addressed.

7.1.1.2 Appropriateness to South Asian disabled people - a proposed interdependent model

Although the Social Model is a valuable concept for explaining disabled people's social exclusion from mainstream life and activities (Vernon, 1999; Swain et al, 2003), it is criticised for concentrating on the social barriers that disabled people experience and failing to acknowledge experiences regarding impairment, ethnicity, gender, sexuality and age that impact upon their lives (discussed in chapter 1) (Ahmad, 2000; French, 1993; Crow, 1996). Regarding South Asian disabled people, the attainment of independence by disabled people is criticised as an inappropriate concept when applied to the lives of some South Asian disabled people (Ahmad, 2000; Atkin et al, 2000; Mir et al, 2001). This is because in South Asian communities, relationships within the family are considered interdependent rather than independent (Ahmad, 2000; Atkin et al, 2000). Therefore the Social Model's focus on attaining disabled people's independence is contrary to South Asian communities' view that their lives are interdependent. This means that the outcome of service provision, which is based on the independence of disabled people (from their families and carers), is inappropriate for South Asian families (Mir et al, 2001). However, from a Social Model perspective independence is about attaining disabled people's control over the decisions that affect their lives rather than these decisions being made by other people (such as carers and professionals). The appropriateness of the Social Model to understanding the treatment of South Asian disabled people within society is discussed in chapter 1, section 1.1.2.4, and is re-iterated briefly here.

Whilst South Asian families are the main buffers against the racism that is experienced by family members and also often the main carers of the disabled members in their families, they can also be oppressive (Ahmad, 1996; 2000). This is because South Asian families (like most other families) are part of a social structure (Harvey, 1990), and have a relationship with social structures that exist in the wider society.

For example, the hierarchical position of people in which one group has power over another, due to gender, ethnicity, age and disability, is reflected in the family. Regarding decision-making within the family, adults are generally in a dominant position to children because children are financially dependent upon their parents and carers, and considered too immature to make decisions (National Children's Bureau, 2003a). The National Children's Bureau argues that:

> *The concept of the democratic family seems inadequate. Children are nearly always in a less powerful position than their parents, and so family decision-making structures are essentially unequal (2003a:1)*

However, non-disabled children might have greater involvement in decision-making processes than disabled children because the ideology that disabled people are incapable and need looking after is reflected in the family as evidenced in this study. Therefore whilst families might be supportive they could also reinforce disabled children's and adults' dependency. However, independence does not necessarily mean breaking away from family support, rather it is about the disabled person 'having a say', and control over decisions that affect their lives. According to Bignall and Butt, many of the Black disabled young people in their study:

> *Suggested that how they lived was as important as whether or not they lived on their own. Being able to make decisions and do things for themselves was an important part of being independent. This, they felt, was equally possible living in a place of their own or with their family (2000b:45)*

This study demonstrated that the Social Model was useful in explaining the social exclusion that South Asian disabled children/young people and their parents experience in their own communities and the wider society (chapter 4 and 5) and especially regarding their access to service provision. From a Social Model and childhood research perspective, I attempted to reduce the barriers that South Asian disabled young people experience in voicing their opinions by

seeking to include these in this study, rather than relying only on the views of their parents and professionals. I did this by acknowledging the interdependent relationship that exists between the parents and their disabled children and involving the parents as key informants in designing appropriate methods for seeking their disabled children's views about their experiences. In future research with this group, they could be involved with the design of the research at the outset because of their participation in this study and therefore familiarisation with the processes involved in research.

Similarly, the concept of interdependency could be used in the interaction between service providers, South Asian disabled children/young people, and their parents to access and provide services that include the views of these three groups. This is because each group has an insight that is relevant to plan services that are appropriate, for example: the disabled young person has an implicit experience of disability and racism; the parents a knowledge about their children and the consequent ability to mediate on their behalf and the service providers have knowledge regarding service provision.

In an interdependent model the views of the South Asian disabled young people would be sought and included, as would those of their parents, carers and professionals. This should enable the disabled children/young people to express their views and therefore offer them choices regarding decisions that affect their lives, rather than other people (usually non-disabled adults) making decisions on their behalf. It would also include rather than shutting out the views of the parents. This concurs with Brett's view regarding the Alliance model for parents who have children with profound impairment:

> *I submit that only a model that is developed around and built upon the experience of the parents and their children will be adequate and appropriate to begin to understand disability from the perspective of profound impairment (2002:831)*

However, the interdependent model differs from the Alliance model, which is based upon negotiation, reciprocity and partnership (I agree with this) between the parents and the professionals (Brett, 2002), but omits the child's presence and view (I disagree with this). Whilst, acknowledging this omission, Brett argues that:

> *I have placed the parent within the model – in the situation of the profoundly impaired child, the parent is likely to be the principal care-giver, providing the key to accessing the child's experience, advocate and 'voice' (2002:837)*

Whilst parents are well placed to mediate for services because of their understanding and familiarity with their disabled children's methods of communication (particularly those with complex needs), placing too great an importance on the parent's knowledge of their children could devalue the children's views. Furthermore, the exclusion of the disabled children's views reinforces their marginalisation from decision-making processes that affects their lives. This need not be the case because the views of disabled children with complex needs can be sought using their preferred medium of communication and methods that are suitable to them (Morris 1998c; Atkinson and Williams, 1990). For example, materials published recently by a number of agencies (listed below, from Listen Up staff workbook, Mencap, undated) that aim to seek disabled children's views in a range of areas that affect their lives could be adapted for use in research:

- Two-way Street: video and handbook aimed to improve practice in communicating with disabled children/young people - Triangle and NSPCC.
- Ask Us! CD-ROM: based on a multi-media consultation involving over 200 disabled children/young people – The Children's Society.
- How It Is (CD-ROM or Booklet: image vocabulary to support children in communicating about a range of issues, including abuse) – NSPCC and Triangle.
- I'll Go First: toolkit aimed for use with disabled children in care planning and reviews – The Children's Society.

- A Lot to Say: practical guide for professionals (social workers, personal advisers) working with disabled children and young people with communication impairments – SCOPE.
- Tomorrow I Go: report containing practical ideas for seeking disabled children's views about services – Triangle.
- Trans-active: project that involves young people with learning disabilities to record their views/choices regarding their future in their 'passports'. Computer games on the website are aimed at helping young people to make choices through their transition from childhood to adulthood.

In the person-centred model, services could focus on the views of the child and could exclude the views of the adults (parents/family) who are involved in the lives of the disabled child, and therefore contribute to feelings of alienation on their part. The Framework for Applying Person Centred Principles (Poxton et al, undated) regarding adults with learning disabilities, suggests that service providers consider the impact of the services that intervene in all aspects of the individual's life. Individuals should also be empowered to make choices (ibid). Whilst the views of the carer are included, the focus is on the individual, which could result in the carer feeling that their role is devalued in the lives of disabled children and adults. This study highlighted that the South Asian parents valued being asked their opinion about various aspects regarding their children's lives and being involved in planning the data collection process with their disabled children. Similarly, the South Asian disabled young people valued being listened to and asked their opinions about their lives. Consequently, the proposed benefit of the interdependent model is that the views of South Asian disabled children/young people, their parents and service providers are included in service provision (including assessments) and are therefore valued. The downside is that the service provider could still be in control of the services that are provided, because they control the resources. However, the real involvement of service users such as South Asian disabled children/young people and their parents should include transparency of the process, including

assessment criteria and resources. This should enable South Asian disabled children/young people and their parents to make informed choices, assess the services they receive and challenge decisions with which they disagree.

7.1.2 Practice

This study contributes to both research practice and working with South Asian disabled children/young people and their parents. It also enabled social change to occur in the lives of the South Asian disabled children/young people and their parents as a result of their participation (discussed in chapter 3, section 3.1.1.1 and below). This demonstrates the appropriateness of using critical social research (CSR) (Harvey 1990), the Social Model (Oliver 1990) and adaptive theory (Layder, 1993,1998) to explore the aspects of disability and racism. This is because these approaches (chapter 3, section 3.1) assisted with the deconstruction of the South Asian disabled young people's, their parents' and the service providers' experiences. These experiences were reconstructed in relation to wider social structures (Harvey 1990; Oliver 1990; Layder 1993,1998), and the role of structural power and dominance in shaping the participants' lives and their interaction with each other, and the wider society. For example, the participants' experiences discussed in (chapters 4, 5 and 6) suggested that the individual model (medical model) and also cultural 'otherness' prevail in society and service provision and influenced the South Asian parents' interaction with their disabled children, which confirmed to the disabled children that they were different because they had impairments and that they required correction and/or rehabilitation to be like their non-disabled peers. An evaluation of the methodology and methods employed in this study is presented in chapter 3, section 3.2.7.

7.1.2.1 Inclusion and social change

This study enabled inclusion and social change in the following ways:

- This study made visible the experiences of South Asian disabled young people by seeking their views about their lives rather than relying upon the views of their parents and/or professionals. In particular, the views of South Asian young people with cognitive, communication and mobility difficulties (referred to as complex needs hereon) and those with visual impairment, were sought because they are generally marginalised in research and service provision. In seeking the views of disabled younger people I:
  - Gained information from professionals, colleagues and the literature about using suitable methods of communication and data collection with disabled children/young people, and those with complex needs.
  - Involved the parents as key informants (at the outset of the study) because they have knowledge about their disabled children's preferred methods of communication and characteristics that helped with designing an appropriate method of data collection.
  - Used my personal and professional experience (prior knowledge) to access the disabled children through their parents. For example, I followed the expected procedure (in some South Asian communities and families) of speaking to the parents first in matters regarding their children, rather than bypassing the parents to communicate directly with the children, which would have been inappropriate. Thereby I respected given cultural 'norms'.
  - Raised the parents' awareness about the research process and also stressed the importance of seeking the views of 'all' the participants. I explained to the parents that appropriate methods of communication and data collection could help with encouraging disabled children to express their own opinions rather than relying on the opinions of their parents, and also that the opinions of the children and the parents are not the same but differ according to the subjective experience of the individual. I also explained to the parents that in general disabled children are often

talked *about* rather than talked *to* and that whilst not everyone might use conventional methods of communication (such as speech) they may have their own preferred methods, which could be used to seek their views, which was what I intended to do (and did). In this way the parents' awareness was raised about the importance of asking their children their opinions about their lives, which resulted in access to their disabled children. Therefore, I used indirect methods, such as raising awareness, to challenge preconceived views about the disabled children's ability to offer their own opinions. For example, whilst the parents of the disabled children with complex needs gave consent for me to approach their children, they also doubted their children's competence to offer their opinions. The process in which the parents were involved as key informants and also as facilitators (some), illustrated to them that with support and use of appropriate methods their disabled children could offer their views. This helped to reconstruct the parents' views about their disabled children's ability to express their opinions in research. The parents could use this method to include their disabled children's views when advocating for services. Furthermore, this study contributes to research methodology by demonstrating that:

- South Asian parents can be involved as a reference group to inform the research by individual telephone and face-to-face contact, rather than meeting in steering groups several times during the study.
- Data can be validated with participants such as the South Asian parents before writing up the findings. The South Asian parents welcomed a group meeting in which they were informed about the findings and my interpretation of their accounts of their lives, which were confirmed as reflecting their experiences.

- The South Asian parents' awareness of their disabled children's (particularly those with complex needs) right to information regarding marriage, in order to make informed decisions about this, was also raised.

- The process undertaken to include the South Asian disabled children/young people in this study helped to familiarise them with the consultation and research process in which their views are sought. This is important in the current political and social climate in which children/young people's views are being sought to inform national and local policy initiatives aimed at meeting their needs (Morris, 2001) such as the Green Paper – Every Child Matters (Treasury Department, 2003).
- By enabling the South Asian disabled children/young people to express their opinions about their lives by themselves, this study helped to increase their self-esteem and self-worth. This is because they were *talked to* (like their non-disabled peers/siblings) which indicated to them that they were listened to (Morris, 2001) and their views were valued (Vernon, 1999), rather than *talked about*, which implies distrust in their ability to offer an opinion. The South Asian disabled young people's willingness to participate in this study suggested that they were not listened to and/or asked about the difficulties that they experienced in their lives because of disability. For example, some of the South Asian disabled young people wanted the interview to stop but wanted to continue chatting with me, whilst other young people such as Rajan described the impact that the diagnosis of impairment had had in his life. Rajan was defined as 'deficient' by society (including his family, friends and services), - a view demonstrated by the notion that he required 'looking after' and/or correction to fit into 'normal' life.
- The South Asian disabled young people were provided with an opportunity to meet with their peers, other siblings and parents through the fun morning that was organised as part of this study. This was an attempt to expand the pool of people with whom they usually interact and to raise their awareness of other children/young people who are in a similar position to them. This is because South Asian disabled children/young people, particularly those who attended special schools and activities seemed to spend their time in supervised company, because these environments are supervised by

adults, and therefore their opportunities to interact with a wider group of people in unsupervised environments is limited.

- The dissemination of the findings through presentations at local, regional and national conferences also helped to make visible the experiences of South Asian disabled children/young people and their parents. The research approach adopted for this study (chapter 3) has been useful in informing the Multi-Agency Disabled Children's Services Co-ordination Project, in Leicester, to include disabled children/young people's views in the planning of disabled children's services. The consultation regarding disabled children/young people's views about the services that they use and would like to use has been acknowledged (informally) by the Audit Commission and Contact-a-Family. The latter is intending to produce guidelines for consultation on which the Multi-Agency Disabled Children's Co-ordination Project is expected to provide feedback (my conversation with the manager).

Summary

This study sought to include the views of South Asian disabled young people and made their experiences visible and heard through dissemination of the findings at conferences and presentations. The South Asian disabled children/young people's participation in this study familiarised them with the research process, increased their self-esteem and provided an opportunity to meet their peers, other siblings, parents and professionals. By involving the parents in seeking the views of the South Asian disabled young people it helped to raise the parents' awareness that their disabled children's opinions could be sought, by using their preferred methods of communication and appropriate methods for seeking their views. This method could also be used with service providers when advocating for services for their disabled children.

7.1.3 Policy

> *Over three decades after the main contemporary period of immigration from the South Asian sub-continent, service providers still had not got effective means of offering services to non-English speakers or to those who are not familiar with the basic structures of the British welfare system (Fazil et al, 2002:251)*

The findings reveal a lack of strategic direction and commitment by service providers to meet the needs of South Asian disabled children/young people and their parents. This could be because institutional racism is addressed in national policy but may not be applied on a local level consistently. I discuss this in relation to the Green Paper – Every Child Matters (at national level) and the element of the Children's Trust (at local level) because it encompasses policy initiatives that are relevant to disabled children/young people. The proposals set out in the Green Paper – Every Child Matters (referred to as the Green Paper hereon) attempt to address some of the difficulties that are experienced by disabled children and their families regarding service provision. These are discussed in relation to South Asian disabled children/young people and their parents' experiences.

7.1.3.1 The Green Paper – the well being of South Asian disabled children/young people

The government acknowledges that investment in children's well being through improving the quality of their lives, which is based upon their views, is important if they are to be valuable members of our present and future society. This is demonstrated by the creation of "*...a new Minister for Children, Young People and Families in the Department of Education and Skills to co-ordinate policies across government" (Treasury Department, 2003:9).*

Children and young people's views have also been sought to inform national initiatives such as the creation of the Connexions service, the Audit Commission report (2003) 'Services for disabled children' and the consultation regarding the Green Paper (Treasury Department, 2003).

The government has recognised that disabled children and adults with learning difficulties are one of the most socially excluded groups in British society, as illustrated by the Valuing People strategy (DoH, 2001), which should benefit all disabled children and adults. The Green Paper specifically attempts to address the needs of vulnerable children including disabled children and BME children by improving services regarding the following four themes: supporting parents and carers; early intervention and effective protection; accountability and integration and workforce reform. I discuss some of the key issues from these themes below. However, the Green Paper has been criticised by the DRC for failing to set targets for improving the life chances of disabled children in recognition of the social exclusion that they experience (Crowther, 2003).

Supporting parents and carers

Whilst the Green Paper outlines the government's intention regarding all children, the priority seems to be child protection and anti-social behaviour. This is demonstrated by the proposals of parenting programmes that include parenting skills.

Disabled children are less likely to come to the attention of services regarding child abuse because they are often not taken seriously (Morris, 1998a/b; Middleton, 1999), and disabled children/young people are generally considered passive and therefore not a problem (Middleton, 1999). However, parenting skills to aid the development of their disabled children could reinforce the professionals' views about disability and the need to rehabilitate the child to be like their non-disabled peers (Ferguson, 2001). If parents do not have prior experience of disability (and awareness of the Social Model) they are likely to believe the professionals (Murray, 2000). Parenting programmes that are culturally inappropriate to South Asian could suggest that their parenting skills are inferior to that of the majority (indigenous) parents. A study by Barnardos, Centre for Research in Primary Care and Centre for Disability Studies (University of Leeds) found that:

> *Parenting programmes generally available for parents of disabled children were described as Eurocentric and therefore, inappropriate. This did little to inspire the engagement of minority ethnic parents, who akin to others had a lot to learn (2002:54)*

The fact that parents of disabled children experience fragmented and ad hoc information and service provision has been recognised. The government proposes that universal services such as education and social care are brought together under one service, preferably under a Director of Children's Services and located within a Children's Trust (discussed later). This is intended to eradicate boundaries that exist between services, which has inhibited the development of cohesion between these services because of different organisational and disciplinary ethos, and funding arrangements. The role of the health services in the lives of disabled children is also being addressed through the National Standards Framework, which includes the working group regarding disabled children (Russell, 2003).

Common assessment frameworks are to be introduced to enable consistency in assessments and to allow a wider range of professionals to undertake this rather than referring the individual to other services. Whilst this might simplify the process of assessment, reduce referrals and the necessity of the parents' re-telling their story to each service that intervenes, it does not seem to address the issue of culturally inappropriate assessments. Consequently, the access to services for South Asian disabled children/young people and their parents is likely to be inhibited by inappropriate assessments.

A national help-line for parents is also proposed to enable parents to seek information, advice and be sign posted to local services. However, this might be inappropriate for South Asian parents, because they might prefer other methods of information provision (Hatton et al, 2002). Chamba and Ahmad (2000) found that the South Asian parents in their study were least likely to use telephone help-lines and preferred information through a key worker, named person, or written information, and also that few of the parents found video and support

groups useful. However, in this study the South Asian parents who attended support groups found these helpful. Another issue is that access to information and services depends upon a person's ability to communicate in English because this is the language that is used to provide both information and services. Chamba and Ahmad (2000) found that South Asian parents who were conversant with English were better informed about services than those who were not. This could be because of the general lack of information and advice about services in languages and formats that meet the needs of those people who are unable to access English and print formats, such as some South Asian parents with disabled children.

This study reveals (chapter 6) that although service providers are aware of the factors (including a lack of appropriate information) that inhibit South Asian service users from using their services, information provision (interpreters and translation) to South Asian service users who did not access English was uncoordinated and inconsistent. Another reason could be because broad policy initiatives, do not explicitly state that the needs of diverse groups such as South Asian disabled children/young people and their parents, are expected to be implemented at a local level. The anomaly between national and local policy is demonstrated by the flexibility that national policies allow for needs to be defined and met locally. For example, service providers could argue that they are faced with using their budget to reach the majority population, and thus do not have sufficient resources to provide information in other languages (i.e. South Asian languages) and formats (Ahmed, 1992). Whilst compiling the information pack for the parents in this study, a range of national, regional, local statutory and voluntary services were contacted for information regarding services for disabled children, BME disabled children and their families. My request for information in South Asian languages included the following responses:

- One local authority (a shire county) suggested that I contact a city authority that might produce information in South Asian languages because of a greater population of Ethnic Minority communities in urban areas (city council).
- In another local authority, despite advertising the availability of information in South Asian languages this was not available at the time of my request.
- A voluntary organisation that provided information in South Asian languages had run out of the information in the language that I requested and consequently offered information in another South Asian language! However, this information was taken and given to a parent who was conversant with this South Asian language too.

This demonstrates service providers lack an understanding that a failure to provide accessible information and services to South Asian users denies them their right to citizenship through accessing welfare services and benefits (Chamba and Ahmad, 2000).

Early intervention and effective protection

The fact that vulnerable children can 'fall through the net' by delayed intervention, and a lack of co-ordinated services and information sharing between relevant agencies was tragically highlighted by the Victoria Climbie case (Treasury Department, 2003). The government aims to improve communication between services by enabling them to share information about children, which is intended to enable them to track the course of child's life through an Identification, Referral and Tracking (IRT) system (Treasury Department, 2003; Russell, 2003). The intention is that services intervene sooner rather than when the child's situation is at crisis point. This should reduce the difficulties that were experienced by the South Asian parents regarding referrals, in this study (discussed in chapter 4). Whilst the criteria for information sharing are yet to be finalised, the down side of IRT is that it could exacerbate the lack of privacy that disabled children and their parents

experience from service intervention. This is because numerous service providers and professionals are involved in the lives of some disabled children and their families, which could result in a greater number of people having details of the disabled children, which could compound their vulnerability (Morris, 1998b).

Another concern is that young people might view sharing of information between services as a breach of their trust especially if they are in contact with a service because of a trusting relationship that they have with a particular service, but not with another. This might deter some vulnerable young people from contacting services that they might require. Similarly, some South Asian parents might not wish for their details (and that of their children) to be shared with services such as Social Services. For example, according to a service provider in this study, South Asian service users were reluctant to be referred via Social Services, which deterred them from using the service. However, despite the IRT, early service provision and intervention is still likely to be based upon the assessment criteria for eligibility of particular services and professional judgement of need. An example, is the SEN Action Programme, which:

> *...will focus on practical measures to promote early identification and intervention for children with SEN, raise expectations and achievement and build the capacity of schools and early years settings, working with health and social care, to provide good teaching and support for all children (Treasury Department, 2003:28)*

SEN support is based upon meeting assessment criteria and the parents' ability to seek SEN support that meets their children's needs. This is based upon their access to information regarding SEN processes and procedures, and support through Parent Partnership Officers. The South Asian parents, in this study, were unaware of this as well as legislation that had an impact upon their children's lives, which restricted their ability to advocate effectively for support that met their disabled children's needs.

Extended schools

In each local authority area a school is to be selected to offer services such as breakfast clubs, after school clubs and community services to make better use of school buildings and to make these central to the local community (Treasury Department, 2003). The position of special schools as possible extended schools is unclear, although special schools might have services that are for disabled children and their families, the actual use of these could isolate them further from mainstream services. However, mainstream extended schools would need to be accessible to all disabled children/young people and their families. This means that other than physical access, non-disabled people's awareness about disability needs to be raised to reduce the social exclusion that is experienced by disabled children, BME disabled children and adults, and their families.

The contribution that BME groups make to the local community through religious education and community activities also needs to be acknowledged with the co-location of these within extended schools. However, this along with other activities needs to be accessible to South Asian disabled children/young people and their parents. The findings (chapter 4 and 5) show that they experience social isolation within their own communities and the wider society because of inaccessible environments and non-disabled people's reaction to disabled people. Consequently, whilst physical access might be addressed due to the DDA 1995, societal attitudes might not, which could prevent this group from using extended schools. This could result in the South Asian disabled children/young people and their parents using specialist disability provision rather than mainstream provision.

Workforce reform

The government intends to increase the skills and experience of staff that work with children, in a range of services and capacities. Regarding child protection this means that staff in children's services might be better trained and informed

to identify children who might be at risk of child abuse. However, training and information regarding child protection (and child abuse) needs to include an awareness of the potential abuse that disabled children/young people might experience. Middleton (1999) argues that disabled children are unprotected because disability workers within disability services fear dealing with abusers because of a lack of confidence in dealing with child protection issues. Conversely, child protection workers working with non-disabled children fear the issue of disability because of their lack of awareness of working with disabled children. Consequently, disabled children 'fall' between disability, and child protection and generic workers (who work with non-disabled children). In integrated services, it should be the responsibility of all workers to identify and deal with child protection issues that affect all children, including South Asian disabled children. This should help to address the failure to identify and address all disabled children's vulnerability to abuse.

Regarding workers, the government acknowledges the need to recruit and retain trained and qualified staff within children's services, including those from BME communities and disabled people (albeit briefly). According to the Green Paper:

> *The children's workforce is diverse, with people entering at various stages in their lives. However, there is considerable scope for encouraging more people from black and minority ethnic groups, more men and more people with disabilities to enter the children's workforce (Treasury Department, 2003:84)*

However, the Green Paper does not explicitly state how the recruitment and retention of BME and disabled people would occur, which suggests reliance upon anti-discrimination legislation to enable their access to employment. Yet, we know that anti-discrimination legislation does not necessarily result in an increase in employment of discriminated groups.

For example, despite the Race Relations Act 1976, BME people continue to experience discrimination within the workforce, resulting in greater levels of under-employment. According to the CRE:

> *Underemployment is considerably higher among ethnic minority communities. In 1998, 5.8% of white people of working age were unemployed on average, but among people from ethnic minorities it was more than double that at 13%. It was 20% for Pakistani people and 23% for Bangladeshi people (CRE, 2003a:4)*

Similarly, despite the DDA 1995, disabled people continue to be excluded from the workforce, which is evident by their invisibility within it including disability services. The following weakness reduces DDA 1995's capacity to address the discrimination that is experienced by disabled people:

- The definition of disability is based on the medical model. In employment, this is illustrated by the onus placed on the individual to prove that s/he is disabled (as defined by the DDA 1995), and that discrimination has taken place (Barnes et al, 1999).
- The DDA 1995 has long lead times to make it enforceable. For example, employers and services have up to 2004 to make their services accessible to disabled people (Drake, 2000).
- The DDA 1995 applies only to those employers with 15 or more workers, which has been altered from the initial 20 (Drake, 2000).
- Access to employment and services are based upon making 'reasonable' adjustment to these. Employers and service providers could justify that making changes to their services could be damaging financially and therefore they could be exempt from complying with the relevant part of the DDA 1995 (Gooding, 2000).
- The 3 % quota to employ disabled people was repealed by the DDA 1995. Although, this was not met, Barnes (1999) argues that similar policies *"...might be reintroduced and strengthened" (1999:17).*

Disabled people's access and retention in work has also been hampered by cumbersome legislation, reduction in benefits and insufficient support (Drake, 2000; Wilson et al, 2000; Morris, 2001). Regarding personal care, direct payments should allow disabled people entitled to this flexibility of how they manage and organise their support, and therefore give individuals freedom to pursue activities that they were previously inhibited to do. According to Hasler:

> *Direct Payments users get more than a choice of bedtimes. The flexibility offered by the system allows people to work, to travel, to be active parents, in short to do the range of things that non-disabled expect to do (2004:221)*

However, in order to encourage disabled people including South Asian disabled people as workers in children's services, the government needs to recognise and address the social exclusion (including support needs) that they experience in accessing the world of work. Failure to do so could result in the under-representation of South Asian disabled workers in children's services and therefore a lack of role models for South Asian disabled children/young people. It will also continue to marginalise their contribution to the economy through employment.

The Children's Trust: Accountability and Integration – locally, regionally and nationally

The Children's Trust is expected to bring together key children's services such as education, social care, some children's health services and could also have the Connexion services and Youth Offending Teams but not all statutory services (Treasury Department, 2003). Whilst partnership working is envisaged (and to be legislated) with the voluntary and private sector, this is open to flexibility. A concern that this raises is that the selection of partners from the voluntary and private sector might exclude BME and South Asian groups. This is because, whilst BME and South Asian voluntary and community groups are used by statutory providers to provide information and services, and vice versa, they are generally not recognised as representatives for their communities at

decision-making levels (Craig et al, 2002). Consequently, regarding children's services established voluntary organisations (such as Barnardos) might be favoured, rather than BME and South Asian voluntary and community groups, to be part of the Children's Trust. This could result in a lack of representation of BME and South Asian children/young people and their parents' needs by representatives who have implicit understanding of their vulnerability due to racism. It could also limit the ability of BME and South Asian community organisations to enable change in the lives of children and young people in their communities, by securing funding which could enable members of their communities to access services. For example, allocation of resources at the planning stage for appropriate information provision to BME and South Asian communities, including disabled members of their communities.

Another concern is that the government is intending to rationalise funding, targets and assessment criteria to reduce fragmentation, key services are to be provided through pooled budgets, where the tension between services to meet their targets is likely to remain. Regarding the delivery of services through pooled budgets, key services could provide these and/or commission this to other providers. This could mean that competitive tendering between the established voluntary sector and the BME voluntary sector (discussed in chapter 6) is likely to continue. Those voluntary organisations that have the expertise and an established reputation (such as RNIB) are likely to be more successful in securing contracts than most BME voluntary and community groups who might lack such status.

In terms of South Asian disabled children and their parents, the creation of the Children's Trust and multi-agency working does not necessarily mean that they will be integrated into mainstream children's services. This is because disabled children could be provided with services through disability services for disabled children. For example, different models of service provision are being used by authorities, which are piloting the Children's Trust.

In one area (existing services for disabled children within education, social care and health are being brought together to create the new disabled children's service, and thus disabled children's services will be part of the Children Trust (Bush, 2003). However, in another area key disabled children's services are to come together under a Disabled Children's Trust, which could isolate them from mainstream children's services. In both of these models, a specialist disabled children's service is likely to continue to promote the view that disabled children are different to their non-disabled peers. The focus on disability also means that ethnicity might not necessarily be considered, as evidenced in this study, and therefore South Asian disabled children's experience of disability and racism could be marginalised. A better way of integrating disabled children in mainstream children's services could be by using the proposal to co-locate workers from a range of children's services in multi-disciplinary teams, which come together to provide co-ordinated services. These teams could include disability workers who work with disabled children and in turn raise the awareness of other workers regarding disability issues. Alternatively, all workers could work with disabled children and receive advice as and when required from disability workers (who could work with disabled children and require specialist knowledge).

Summary

The Green Paper should help to provide co-ordinated services to children and their parents which are aimed at the following outcomes: *"being healthy"*, *"staying safe"*, *"enjoying and achieving"*, *"making a positive contribution"*, *and "economic well-being" (Treasury Department, 2003:14)*. However, the proposals are unlikely to eradicate the barriers that South Asian disabled children/young people and their parents' experience regarding their access to service provision that meets their needs because of the failure to include targets for achieving change for disabled children. Another reason is that whilst institutional discrimination is addressed in national and local policy its application in practical terms at a local level could be difficult because at a local level policy-makers and planners of services might meet the needs of the majority rather than the minority, by justifying that this is an effective use of resources. Unless institutional discrimination is integrated in national and local policy South Asian disabled children and young people and their parents will continue to be marginalised. For example, integration of national policy to implementation at a local level has been started by the RR (A) 2000, which requires local authorities to publish a Race Equality Scheme setting out how race equality will be met and measured in each of its duties. This became part of the Equality Standard for Local Government which expects local authorities to set standards (Equality Impact Assessment) to implement and achieve equality regarding disability, race and gender (and could also include religion and sexuality) within its services and functions.

7.2 Recommendations and future work

This study explored the experiences of South Asian disabled children/young people and their parents, and their access to service provision. In this section the main recommendations (stated below) are aimed at improving their access to service provision and therefore their citizenship.

Strategic direction

There is a need for national policy for children and families to provide strategic direction to address the needs of children and their carers arising out of institutional disability and racism. The CRE, DRC and EOC, which advise government on policy regarding racism, disability and sexism respectively should work together to promote the inclusion of BME disabled children and their families. The recent government proposal to merge these three bodies should provide the new single body (Commission for Equality and Human Rights - provisional name) (The Times, 2003:4) which should help with considering disability, race and gender (equality issues) in a holistic way. However, some disabled people have expressed concern that the issue of disability could be *"...marginalised by issues with a higher political priority or that exert greater political pressure"* (Brown, 2002:20).

Disabled people and their organisations which are *of* disabled people (such as BCODP rather than organisations *for* disabled people such as RNIB) are better placed to inform advice agencies such as the CRE, DRC, EOC about local needs arising out of disability and racism. This is because disabled people in organisations *of* disabled people (working as activists) have been instrumental in establishing and managing these themselves, and their influence on policy and practice is a consequence of their experiences of social exclusion. Whereas organisations *for* disabled people (traditionalist in outlook) have historically been established by non-disabled people and managed by them in the perceived interest for disabled people. Their influence on policy and practice is likely to be more about appeasement than change in the lives of disabled people (Barnes et al, 1999). A clear and formal channel of communication needs to be established between disabled people/ BME disabled people and their organisations, and the CRE, DRC and EOC, through which communication can flow between these groups to inform national and local policy. The Children's Trusts should provide the opportunity for the formation of multi-agency teams to promote multi-disciplinary working practices.

Direct communication - outreach work

Service providers should market their services through direct communication such as outreach work to South Asian disabled children and their parents, because this is a more effective way of informing them about services. Direct communication also enables the information to reach the person for whom it is intended and therefore reduces the dependency of South Asian disabled children and adults upon their carers and other people (non-disabled) in their communities. Direct communication allows individuals to select the information they require rather than receiving information that is based upon the judgement of other people (usually non-disabled).

There is a need for networking to be established between specialist services such as disability and BME services. This should enable workers from a range of specialist services to access information, knowledge and expertise to make their services disability and culturally sensitive.

A community development approach to raising awareness about disability and racism.

All workers who work within an equal opportunity policy framework (most organisations have one) should raise awareness about disability and racism, and the impact of disadvantage on service users (BME disabled people and their carers) in team meetings, supervision and policy forums as a means of improving policy and provision. These workers should be provided with support, training and networking opportunities to broaden their knowledge.

Awareness campaigns regarding disability should be led by disabled people and their organisations (national, regional and local) because of their knowledge regarding the discrimination that disabled children and adults experience from the perspective of the Social Model.

Disabled people, BME/South Asian disabled people and their organisations should work with both the DRC and the CRE, to bring together issues relating to disability and racism at a national policy level.

There is need for BME service providers to take the responsibility to ensure that awareness is raised within their communities (including caste/jati and faith groups) regarding equality issues and legislation. In terms of disability issues, BME service providers should liase with disabled people and their organisations (both within their communities and in wider society) to utilise their skills and knowledge to raise awareness within BME communities and also with key members of BME organisations. For example, at a national level through associations such as the National Council of Hindu Temples (UK), The Muslim Council of Britain and The Network of Sikh Organisations (UK), which should help to inform their members about disability issue. In this way therefore it could help to make their communities inclusive in their attitudes and activities towards the disabled members of their communities.

7.2.1 Future work

Whilst there is information and research regarding sex and sexuality (Fairbairn et al, 1995; Gregory et al, 2001; McCarthy, 1999; Shakespeare et al, 1996) there is a lack of information regarding the experiences of BME disabled people in this area. The views of BME/South Asian disabled people (through future research) are important because it would increase understanding about their respective needs for disability and culturally sensitive information and also for increased opportunities for their own (unsupervised) encounters with their peers in which they could access the information and support they require regarding these matters.

As already mentioned, networking is another area in which further developmental work and research is required. There is a need to establish networking between specialist services such as disability and BME services and

to investigate the opportunities that workers, particularly those that work directly with disabled people and BME people, have to engage in networking activities. This should inform policy and practice regarding the training and support needs of workers who provide direct services to disabled and BME people within disability and BME services.

7.3 Conclusion

In this section, I conclude this study by evaluating how it has met the following four requirements of a PhD, stated in the University's Research Degree Regulation (2000:3).

A demonstrate an understanding of research methods appropriate to the field of study

B demonstrate critical investigation and evaluation of the topic of research

C constitute an independent and original contribution to knowledge

D demonstrate the candidate's ability to undertake further research without supervision

A demonstrate an understanding of research methods appropriate to the field of study

A multi-strategy and multi-methods approach (Layder, 1993) was used to select the most appropriate methods (in this study qualitative methods) of data collection with the three groups of participants (discussed in chapter 3). This is because it allows the methods to be chosen nearer the time of the data collection, which means that methods do not have to be prescribed prior to the research, but could be chosen according to the situations that are presented in the research and therefore would be driven by it. This fits with CSR, which does not rely on one method of data collection, but suitable methods, which is important when researching disabled children from a 'new sociology of childhood' perspective, as it advocates the inclusion of disabled children's views in research rather than relying upon the views of adults (Shakespeare and Watson, 1998; Moore et al, 1998; Morris, 1998c).

From CSR, Social Model and childhood research perspectives, relying upon the views of adults rather than seeking the disabled children's views would have re-enforced their silence and therefore the oppression that they experience in being denied a voice. The process of seeking disabled children's views in this study (as mentioned before) which involved seeking advice from professionals and using parents as key informants enabled me to reduce barriers to accessing the disabled children such as:

- parents as gatekeepers
- lack of understanding about their preferred methods of communication which could result in disabled children/young people's views not being sought
- adult based methods and language in data collection that are unsuitable when researching children. Researchers have suggested use of child-based and age related methods, including use of appropriate language when researching children (Alderson and Goodey, 1996; Ireland and Holloway, 1996; Mahon et al, 1996; Beresford, 1997; Moore et al, 1999; Thomas and O'Kane, 2000; Connors and Stalker, 2003).

In this study, the parents and professionals suggested the semi structured interview with the disabled younger people as the best method of data collection. The semi-structured interview allowed communication between the participant and the researcher, which enabled both parties to seek clarification if required. It also allowed the participants to tell their story about their experiences and/or talk about issues as they wished. The parents and professionals were also able to help with identifying the preferred communication needs of the disabled young participants, which is important because South Asian disabled children/young people are not a homogenous group, and therefore they might require methods that are tailored to their individual needs, such as communication. For example, in this study information about the research was made available in large print and facilitators (as suggested by Atkinson and Williams, 1990) were used (as required) to assist in the data collection with disabled children/young people with cognitive and

communication difficulties, to enable communication between the researcher and the disabled younger participants. The parents and professionals were asked to help with identifying which disabled younger participants might require a facilitator and also to help with enlisting a facilitator who was familiar to the participant. A failure to recognise barriers that disabled children/young people experience in voicing their opinions such as reliance upon the views of adults, inappropriate methods of communication and data collection, and their need of a facilitator could have prevented data collection and/or resulted in inappropriate interaction with the disabled younger participants thereby re-enforcing the oppression they experience because their needs are overlooked.

Prior and existing knowledge such as my professional experience and the available literature (Burke and Miller, 2001; Frey and Oishi, 1995; Lavrakas, 1993) were used to select the telephone interview as a suitable method for data collection with the service providers (chapter 3, section 3.2.4.2). This proved more effective in interviewing a greater number of people (22) in a shorter space of time than was likely with methods such as the face-to-face interview. Aspects that were considered in designing the interview schedule and conducting the interviews included a consideration of the use of the telephone by representatives (employees) within their organisations (because other employees could use one telephone line). Employees also engage with prevailing social structures that are oppressive and therefore any information that is given about their organisation that could be considered as a criticism brings into question the employee's loyalty to the service. Therefore, the questions were asked with sensitivity and responses were not challenged.

For all three groups of participants, the ethical considerations examined included aspects regarding consent, confidentiality and anonymity, in an attempt to prevent possible risk of harm as a result of their participation in this study (chapter 3, section 3.2.5).

Furthermore, prior knowledge (my personal experience of racism and professional experience – employment at RNIB, and other areas of youth and community work) informed me of the practical barriers that could prevent the participation of the South Asian disabled children/young people and their parents in the research, which were considered, such as communication needs, venue (transport) and domestic/caring responsibilities. Aspects such as the parents' and their disabled children's experiences of social exclusion in British society (due to immigrant status and ethnicity) were also considered. For example, semi-structured interviews were conducted with the parents rather than postal questionnaires because their literacy in their own languages and/or English could not be assumed. If questionnaires had been sent the parents might not have been able to communicate directly with me (in some cases in Gujarati) and get extra information about services such as Social Services and Education (Parent Partnership schemes). The parents were provided with interpreters who translated questions in their own South Asian language as required. They were also offered a choice of a venue (although most were interviewed in their homes). The research approach was also sensitive in that, for example, data collection was conducted according to the times that were suitable to the participants. School holidays, including half term and festivals (Diwali, Ramadan and Eid) were generally avoided for data collection, as this was preferred by the parents. Contact with the parents was also minimised, if it conflicted with a wedding or bereavement in the family.

The above aspects could have acted as barriers to participation in research if they had not been considered. These aspects were also sensitive to prevailing assumptions of social structures as oppressive to South Asian parents and their disabled children and also those employees working within service provision engage with oppressive social structures.

B demonstrate critical investigation and evaluation of the topic of research

In this section, key findings from chapters, 4, 5, 6 and 7 (section 7.1) are presented. These chapters demonstrate that the research topic has been critically investigated and evaluated with the use of the theoretical and analytical framework adopted for the study (discussed in chapter 3, section 3.1) which was underpinned by CSR because:

> *It is concerned with revealing underlying social relations and showing how structural and ideological forms bear on them. Critical social research, then, is interested in substantive issues, and wants to show what is really going on at a societal level. Not only does it want show what is happening, it is also concerned with doing something about it (Harvey, 1990:20)*

The Social Model (Oliver, 1990) assisted with explaining the treatment of the South Asian disabled children/young people and their parents by society and service providers, and therefore identifying the social barriers that prevent their inclusion in mainstream life and activities. Adaptive theory (Layder, 1993, 1998), helped to link South Asian disabled children/young people's and their parents' experiences to wider social structures and consider ways in which they were excluded from mainstream life and activities. As mentioned before the common principle of enabling social change in the lives of the participants, advocated by CSR (Harvey, 1990) Social Model (Oliver, 1990) and emancipatory research (Priestley, 1997, 1999; Oliver, 1997) was met in the following ways (summarised from chapter 3, section 3.1.1.1):

- Reconstructing the South Asian parents' perception of their disabled children's ability to offer their opinions through participation in activities such as research, by using an approach in which they (parents) were involved to enable their disabled children's participation. A similar approach in which disabled children's views are sought could be used in mediating for services with service providers.

- Raising the parents' awareness about their disabled children's right to information concerning aspects of social life such as marriage, so that they could make informed choices about such issues rather than be denied this opportunity.
- Raising the self-esteem of the South Asian disabled young people who participated in the research by *talking to* them about their views concerning their lives rather than *talking about* them.
- Increasing familiarity of the South Asian disabled young people with the research process, which could help with their participation in future research and consultation based exercises.
- Helping to extend the pool of people such as other South Asian disabled children/young people, siblings and professionals with whom the disabled young participants in this study might not have had previous social contact.

South Asian parents' experiences

The first aim of the study was to explore the experiences of South Asian parents of disabled children, including their access to services provided by statutory and voluntary organisations. The findings (chapter 4) reveal that the South Asian parents experienced additional pressure in mediating for services with service providers and in supporting their disabled children. The issues that added to the pressure that they experienced include:

- Disabling environments (negative attitudes towards disabled people and inaccessible venues) within their own communities and the wider society. The treatment of disabled people by the general public demonstrated the individual model and cultural 'otherness'. The South Asian disabled children/young people and their parents experienced social exclusion from disability services and BME services, which focused on disability and ethnicity respectively, but not both. Consequently, their experiences of disability and racism were not understood and addressed by either of these services.

- The South Asian parents' view that disabled people's participation in mainstream life and activities depended on their *"disability"* influenced their interaction with the disabled children. For example, only two parents had aspirations for their disabled children's future. Whilst the parents of disabled children with complex needs had watched disabled people participating in training and employment on television, this did not seem to alter their view about their disabled children's potential to engage in these activities in the future. This could be because disabled children, who attended special schools, were taught social and life skills, rather than academic and transferable skills for employment, which suggests that education professionals and parents seemed to have low expectations about the ability of children with complex needs to fulfil their future potential.
- A general lack of understanding regarding disability within the South Asian communities, which inhibited the South Asian parents' ability to socialise within their own community groups, because of disabling environments. Not all the parents were well supported by their extended families, which refutes the commonly held perception (by service providers) that they are supported within their own communities.
- The parents did not have prior experience about disability and thus were influenced by the professionals' knowledge regarding their children's impairment and rehabilitation through medical treatment and/or specialist services to be like non-disabled children. The parents searched and hoped that their disabled children would improve and eventually be like their non-disabled peers, an attitude which was also internalised by Rajan and Rajeev who wanted to be 'normal' and wanted the same opportunities as their non-disabled peers.
- The South Asian parents' ability to advocate for services and support for their disabled children was restricted by a lack of access to information regarding their children's impairments, services that were available and their children's future. There was also a general lack of awareness regarding legislation and policy that was relevant to them and their disabled children

such as the DDA 1995 and SENDA 2001, which reduced their ability to access their rights and therefore citizenship.

South Asian disabled children/young people's experiences

The second aim of the study was to explore the experiences of South Asian disabled children and young people. The findings (chapter 5) reveal some insights (stated below) into the experiences of the younger participants. The greatest amount of data was received from interviews with two participants, particularly Rajan, who responded more fully to the questions being asked. The rest of the participants (4) responded with yes/no or short answers and also used Makaton (and/or gestures). They also preferred to talk about aspects unrelated to the questions such as a recent incident in the family and a forthcoming wedding and birthday. Findings comprise the following:

- The South Asian disabled younger people were treated differently (to their non-disabled peers) because of being defined as disabled. Although the South Asian disabled younger people liked similar things to their non-disabled peers their access to social life was restricted because of disabling environments, in which they experienced negative social attitudes and inaccessible buildings and activities.
- The South Asian disabled younger people (particularly Rajan) were aware that they were treated differently, although not all were aware that this was because of disability. However, the disabled younger people responded to being treated differently (i.e. being stared at, called names) by isolating themselves from their non-disabled peers.
- Bullying was experienced by two of the younger participants, although not all talked about bullying and/or unhappy experiences in their lives. This could be because they were generally not encouraged to do so and/or because they may be unable to 'name' concepts such as abuse and discrimination (Morris, 1998b). It could also be because the mechanisms to recognise, report and address the abuse that disabled children/young people

experience fails to protect them because of their devalued position in society (ibid).

- The South Asian disabled younger people who attended special schools/colleges and activities spent their time in supervised company (with adults and/or non-disabled siblings). This limited their opportunities to socialise with their peers in a wider range of settings such as their local neighbourhoods and mainstream leisure and recreational facilities including youth clubs, and thereby access the experiential learning that occurs in such settings.
- Only one young participant mentioned marriage, which could be because a question about this aspect was not asked. This person considered marriage as a future aspiration, which differed to the view of his parent (mum) who doubted his competence to understand the concept of marriage and parenting. This could pose a difficulty for this young person to fulfil his aspiration of marriage.
- Only one young participant (Rajan) was aware of the formal support that was available to disabled children and the discrimination that disabled children experience. Rajan talked about his individual experience of impairment and its impact on his life such as his experience of being bullied, his need for support and also his aspiration to be independent. However, the rest of the participants talked about the social aspects in their lives such as forthcoming birthday (Jamila), wedding (Imran/Faraaz), and an incident in the family (Ajay).
- The South Asian disabled young participants had aspirations for the future, which included further/higher education, travel, holidays, and employment, which is similar to the aspirations of many non-disabled young people. It is the case however, that disabled children/young people's ability to achieve their aspirations is likely to be inhibited by the disability and racism that they experience in society.

Service providers' experiences

The third aim of the study was to explore service provision for South Asian parents of disabled children and young people and how service providers perceive South Asian disabled children and their parents. The findings (chapter 6) suggest that:

- Disability service providers tended to focus on disability issues and BME service providers on ethnicity but not on both. This meant that BME disabled children/young people and their parents 'fell through' services that did not address their experience of both disability and racism. This also meant that the South Asian disabled children/young people and their parents were compelled to use disability services that understood issues that related to disability, but which did not understand their experiences of racism and the need for culturally appropriate services.
- Whilst the majority of the service providers were aware of the barriers that are experienced by BME and South Asian service users in accessing their services, and were attempting to address these, the barriers persisted. This could be because of a lack of commitment at the policy and planning stages to allocate appropriate resources at the outset for making services accessible to BME and South Asian users. For example, information provision to South Asian users was uncoordinated and inconsistent, despite the common knowledge that information is the gateway to accessing services, rights and therefore citizenship. There seemed to be a reluctance to provide information at the outset that was appropriate to users who were not conversant with the English language, such as some South Asian users. For example, some services provided translated information and interpreters upon request, which means that the user would need to know about the service in the first place. Yet, this study reveals that South Asian families with disabled children are generally unaware of services and therefore have difficulty in accessing these.

- Service providers seemed to rely upon strategies such as targeted campaigns ('word of mouth') within South Asian communities to inform them about services. However, there seemed to be a lack of recognition of the negative social attitudes and inaccessible venues that South Asian disabled people experience within their own communities, which could result in their reluctance to socialise with their peers within these communities. Therefore targeted information campaigns, to religious places, community groups and events frequented by South Asian communities were unlikely to directly reach South Asian disabled people. Consequently, they might rely on their non-disabled family members and relatives to pass on information, which reinforces their dependency on non-disabled-people.
- Direct communication such as outreach work was a more effective way of informing the South Asian disabled people and their families about services, and thus increasing their use of services.
- BME staff increased the use of services by BME users and also enabled services to be culturally appropriate. Despite this, the majority were employed in short-term projects, which suggests that service providers perceive the needs of this group to be a short-term issue and/or are unwilling (or unable) to apply sufficient funds.
- There was general lack of reassurance that services are culturally appropriate (or are attempting to be so). Culturally inappropriate services were considered by the service providers to inhibit use of their services.
- The service providers experienced funding restrictions, which limited their ability to expand their services to meet the needs of a wider group of people and to develop longer-term initiatives. BME voluntary and community groups experienced greater difficulties in securing and retaining funds.

C constitute an independent and original contribution to knowledge

Since this study began in 1998, there has been an increase in knowledge regarding the experiences of BME and South Asian disabled children/young people and their families (Chamba et al, 1999; Bignall and Butt, 2000b; Flynn, 2002; Hatton et al, 2002; Hussain et al, 2002; Patel, 2002; Skill, 2003b). Therefore the findings of this study confirm existing knowledge (chapter 2) about their experiences of social exclusion and that despite an increased understanding of the barriers that are experienced by this group and the attempts by service providers to address these, the barriers have persisted. However, this study differs from existing studies in a number of ways (stated in chapter 1, section 1.3) in particular the theoretical and analytical framework (discussed in chapter 3, section 3.1 and mentioned above) sets it apart from other studies. For example, the research process aimed to enable social change (small changes were made as mentioned earlier in the chapter and also in chapter 3) as per the principles of CSR, Social Model and emancipatory approaches. Furthermore, CSR (Harvey, 1990) and adaptive theory (Layder, 1993, 1998) helped to reconstruct the participants' experiences which adds to knowledge, according to Harvey:

> *Knowledge is dynamic, not because we uncover more grains of sand for the bucket but because of a process of fundamental reconceptualization which is only possible as a result of direct engagement with the processes and structures which generate knowledge (Harvey, 1990:23)*

The input to knowledge this study makes is discussed earlier in this chapter (section 7.1) and therefore the main original contribution is summarised below.

- This study demonstrated that the Social Model is appropriate for explaining the treatment of South Asian disabled children/young people and their carers by society and service providers. For example, it was identified that whilst there is some awareness of the Social Model within services the individual (and medical) model determined the interaction between society, service providers, the South Asian parents and their disabled children.

For example, the South Asian disabled children/young people and their parents experienced disabling environments (negative social attitudes and inaccessible services and activities), which resulted in their social isolation. This was compounded by their experience of disability and racism, which was addressed by disability and BME services as separate issues. This means that they missed out on services that met needs arising out of disability and racism.

- An interdependent model is proposed to acknowledge the interdependent relationship that exists in some South Asian communities, so that disabled children/young people within these families are included within decision-making processes that affect their lives. It should also help to avoid the exclusion of disabled children's/young people's views in decision making processes, due to the possible taken-for-granted assumption that their opinions are represented within family decisions because of the interdependency that might exist. For example, Imran-Faraaz (disabled young participant) according to his mum wanted the same item of clothing and equipment - mobile phone – as his non-disabled siblings (mentioned in chapter 5). It is unclear whether Imran/Faraaz and his siblings were involved in deciding the items of clothing and equipment that were purchased for them. However, it seems that Imran/Faraaz might not have been consulted and if he was his preference not considered, because he was given a toy mobile phone rather than an 'actual' mobile phone. This suggests that whilst there is an assumption of interdependency within South Asian communities and families the preferences of every member of the family might not be sought and/or heard. This is because interdependency does not necessarily mean that the views of every member of the family are taken into consideration, because the structural hierarchy that exists within society is often reflected in family structures. In the interdependent model the structures that exist in society and the family are acknowledged and therefore it maintains that everyone concerned with the disabled child's welfare, including the disabled child should 'have a say' in matters (such as

service provision) that affect their lives. In seeking to include the views of the South Asian disabled children/young people in this study, the interdependent relationship that exists in some South Asian communities was acknowledged. The South Asian parents were involved in the research at the outset as key informants, which along with respecting cultural 'norms' helped to gain access to their disabled children. It was stressed in the research purpose (explained to the parents) that the aim in the study was to seek 'all' the participants' views from themselves, and that their disabled children's preferred methods of communication would be used to communicate with them. This process of seeking the disabled children's views helped to reconstruct the parents' perception about their disabled children's ability to offer their opinions about their lives.

- This study demonstrated that South Asian parents (participants) could be involved in the design of the research through telephone contact on an individual basis, and that they do not necessarily have to meet as a steering group to inform the research. The telephone contact with the parent personalised their involvement and allowed greater participation because they did not have to consider the logistics (such as care, transport and time) to attend steering group meetings. However, the majority of the South Asian parents did attend a group meeting to validate the main findings from their interviews before they were written up.
- Direct communication, such as outreach work is a more effective way of providing information directly to South Asian disabled children/adults and their carers. This is because targeted information campaigns to South Asian communities are unlikely to directly reach disabled members of these communities. This is because South Asian disabled children/adults and their carers are less likely to congregate with their non-disabled peers because of negative social attitudes towards disabled people and inaccessible venues, which results in their exclusion from socialising with their non-disabled peers. Indirect methods such as targeted campaigns to South Asian

communities in places that they frequent such as religious venues can result in service providers relying upon non-disabled people to pass information ('word of mouth') on to disabled members.

D demonstrate the candidate's ability to undertake further research without supervision

By conducting and completing this study a number of skills have been enhanced which should enable future research to be conducted without supervision such as:

- Project management and organisational skills. For example, setting the aims and objectives of the study and meeting these within competing demands and deadlines imposed by the study together with those of personal and professional demands. Organisational skills were honed by planning of the group meeting and the fun morning, which involved consideration of logistics (such as: budget, transport, language, diet, childcare and support). The assistance of volunteers with an appropriate background in social care and play was also enlisted. The free use of play equipment from a local voluntary organisation was negotiated. This improved my negotiating skills and confidence to ask for assistance from other people, particularly without charge. This experience was helpful in my present post in which consultation events for disabled children and young people were organised in partnership with workers from statutory and voluntary services. Assistance (without charge) was negotiated from students at De Montfort University who established a music label 'Future Innovation'. The students developed a computer software package for music, which was assessed for accessibility to disabled children and adults (as part of the students' module). The computer software package (CD) was also given (free of charge) to the disabled children, their families and workers who attended the events and/or requested this. The students were also invited to participate in other events for disabled and non-disabled children and young people.

- Communication and interpersonal skills. For example, during this study support and participation from a wide range of people was gained including South Asian disabled children/young people, their parents and service providers. Both direct and indirect methods were used to encourage participation in this study from the three groups of participants, which resulted in the finding that direct methods were better. The research methods and findings were presented to peers (academic and professional) at conferences and lectures. Within the lectures the Social Model was promoted and exercises regarding communicating with disabled people (who are not a homogenous group) were conducted. These raised the students' awareness of the importance of communicating directly with disabled people to enable them to express their views regarding decisions that affect their lives and also to have control over their lives. The findings were also disseminated through conference papers, which along with writing this PhD thesis has improved my writing skills.
- The theoretical knowledge (theoretical and analytical framework, disability theory) and practical experience (qualitative research methods) of researching disabled children and young people gained during the PhD study informed the consultation of disabled children and young people in Leicester about services that they might use (for the Multi-agency Disabled Children's Co-ordination Project). The ethical research practice that was employed in the PhD also informed the consultation, for example, the disabled children and young people (as far as possible) were given the opportunity to participate in the consultation activities and to express their views regarding their preferred methods of communication (with support as relevant). The dissemination of the consultation findings and outcomes will take account of the diverse needs of different groups of people. For example, in this study the videos of the interviews with South Asian disabled young people were given to them at the end of the study. Different summaries (appendix 7a, 7b and 7c) that used the terms that are familiar to each group were produced and given to the participants as relevant.

The parent's summary was translated into the main language (Gujarati) that was spoken by them. A similar process will be followed within the consultation project and a feedback event for disabled children and young people organised. As mentioned before, the consultation activity has been recognised by the Audit Commission, Contact-a-Family and Children's Services in Leicester. Other service providers are seeking advice about consulting children and disabled children about their services. The skills and theoretical knowledge have also been used to review the research that has been commissioned by the project and also to inform writing journal articles, report writing and the strategic direction for disabled children's services within Leicester. My understanding of the Social Model increased during the PhD study, which is evident through the use of terms such as disability/condition (rather than impairment) at the beginning of the study (Appendix 1 and 3) when I was employed at the RNIB where such terms were used. However, during the study as my understanding increased my terminology changed as evidenced in the definition of the Social Model (chapter 1).The research skills (using various sources including the Internet for information and the ability to note these accurately) and methods (semi-structured, telephone and group interview, and observation) gained during this study has informed the following:

- The literature search (England, Wales and Northern Island) and practice visits (England) that were conducted for a review regarding the access to short-break services by BME disabled children and their families for the Joseph Rowntree Foundation (Flynn, 2002).
- Data collection, collation, analysis and report of Black children and families' contact with Nottinghamshire Social Services (conducted for the Centre of Social Action, De Montfort University).
- Design of methods (questionnaires, semi-structured interviews, focus groups and meeting to disseminate findings) for a research project that involved peer group researchers investigating the views of BME young

people regarding youth services provided by Leicestershire County Council.

- Research design, including ethical practice (including meeting diverse needs and communicating with people at all levels), organising the fieldwork and undertaking community development work, data collation and analysis, and co-writing the report for a research project for Barnardos Midland region. The research was regarding the use of short-break services by South Asian children and their families in a shire county in England (Flynn and Patel, 2002). The research project and approach required knowledge about working with BME and South Asian communities, disabled children and their families.

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Appendix 1
Criteria for a purposefully selected sample

Group	Criteria
South Asian parents	- Are of South Asian origin - Are parents of a South Asian disabled child - Reside within the six local authorities - Receiving services from: statutory services, voluntary and community organisation.
South Asian disabled children/young people	- Are of South Asian origin - Have a disability/condition - Reside within the six local authorities - Receiving services from: statutory services, voluntary and community organisation.
Professionals (service providers)	- Provide services to disabled children/adults and/or their carers - Provide services to BME/South Asian communities - Provide services to children/families

Appendix 2a

Flyer for Asian parents of a child with a visual impairment

HAVE YOUR SAY!

- Are you an Asian parent of a child, who is blind or has serious sight problems?

- Are you, or do you know of, an Asian young person who is blind or has a serious sight problem?

- Do you want to talk about the services that you are getting? (or would like to get)

If your answer to any of the above is ***YES*** - then talk to me!

I am talking to young people, and Asian parents who have a child with a serious sight problem, as part of a research project that aims to improve services.

Anything you say to me will be confidential. I can talk to you in your home or in your child's school or college. Your experiences will be put together with information from other Asian parents so that I can write about what is needed to improve services.

So what do you get by talking to me?

➔A listening ear!
➔Information pack of local services that you may find useful.
➔I can put you in touch with local and national services that may be able to support you.

To find out more or to arrange for a suitable time to talk to me please phone: 0116 2629636. Alternatively, complete and send the reply slip below or ask your child's teacher to contact me.

~~~~~✂~~~~~
~~~~~

Appendix 2b
Flyer in English – disabled children

HAVE YOUR SAY!

- Are you an Asian parent of a child, who has a hearing impairment or a disability?

- Are you, or do you know of, an Asian young person who has a hearing impairment or a disability?

- Do you want to talk about the services that you are getting? (or would like to get)

If your answer to any of the above is ***YES*** - then talk to me!

I am talking to young people, and Asian parents who have a child with a serious sight problem or hearing impairment or a disability as part of a research project that aims to improve services.

Anything you say to me will be confidential. I can talk to you in your home or in your child's school or college. Your experiences will be put together with information from other Asian Parents so that I can write about what is needed to improve services. An interpreter will be made available if needed.

So what do you get by talking to me?

➔A listening ear!
➔Information pack of local services that you may find useful.
➔I can put you in touch with local and national services that may be able to support you.

To find out more or to arrange for a suitable time to talk to me please phone: 0116 2629636, or complete and send the reply slip below or ask your child's teacher to contact me.

~~~~~✂~~~~~
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Appendix 3
Flyer for assistance from service providers

Do you work with an Asian child with a Visual Impairment, Hearing impairment and/or a disability?

Do you know of someone who does?

If the answer is **YES** – then you can help me!

What can you do?

- Inform Asian parents of the Asian children that you work with about the study
- Inform someone you know about the study
- Ask Asian parents to get in touch with me directly or through yourself

What is the study about?

The experiences of Asian young people and Asian parents who have a child with a Visual Impairment, Hearing Impairment and/or a disability, about the services that they get and would like to get. This is as part of a course (MPhil/PHD) at De Montfort University.

What will it involve for Asian parents?

- Meeting and talking to me for about 1-2 hours, at a suitable time and place to them
- What parents tell me will be confidential and will be put together with information from other Asian parents to improve services
- An interpreter will be made available if needed

What will parents get?

- Someone who will listen to them
- Information pack of local services
- I will put them in touch with relevant local and national services

How to contact me:

Telephone: 0116 2629636 or 0116 257 7796 or write to:
Pratima Patel, Research Student
De Montfort University
Dept.of Social and Community Studies
Scraptoft Campus
Scraptoft
Leicester LE7 9SU

Appendix 4
Letter requesting support – Service providers

Date as Postmark

Dear …

Re: MPhil/PhD research study

I am Pratima Patel and am employed with the RNIB Asian Families Project. As a Family Support Group Liaison Officer, I work directly with Asian parents and families who have a child with a serious sight problem (blind and partially sighted), and who live in the West Midlands.

In the past two years that I have been working within the project, I have found a lack of documented material concerning the experiences of Asian parents. Therefore I have decided to embark upon research to find out what their experiences are by conducting an in-depth study in my own time.

I intend to conduct my study within (England). The groups of people that I envisage participating in the study are: Asian parents who have a child with a serious sight problem; Asian children and young people who have a serious sight problem and professionals working with these Asian parents and/or their child.

In order for me to conduct this study successfully, I would appreciate your support to:

- identify those relevant professionals within your service who are willing to participate in the study;
- identify, and put me in-touch with those Asian parents who are known to your service.

I would appreciate an opportunity to discuss this further with you. Please find attached aims and objectives of the research study for your information.

Primarily I am looking for direct contact with appropriate professionals for example: Teachers of the Visually Impaired; Rehabilitation workers; Social workers; Community workers; etc., in order to obtain the information necessary for my research. Therefore, I would be grateful if you could send me a list of relevant personnel as soon as possible, preferably by **31st May 1999**. All respondents participating within this research will be offered confidentiality.

If you have any queries or would like further information please contact me on 01203 369 557, or e-mail xxx.

Yours sincerely

Pratima Patel

Appendix 5

Main themes emerging from the South Asian parents' interviews

Experiences of Asian parents of having a disabled child:

1 FINDING OUT

Child's behaviour
Medical Intervention
- Staff
- Information
- Counselling

2 EMOTIONS EXPERIENCED

Reasoning – how come?
- Blaming
- Religion
- Coping

Normal – looks OK
- Gets better
- Cure

3 CHANGE – EXTRA RESPONSIBILITY

- Caring and Supervision
- Looking after
- Safety and protection.

Worry

Future

4 DISABILITY AND DIFFERENCE

Awareness
View of their child – like other children
Reaction of other people

5 SUPPORT

Family, friends, etc.
Barriers
Organisations and services
- Experience of service provision

Appendix 6a
INTERVIEW PROCEDURE

South Asian parents Code No.

Introduce: myself, the course, purpose of study and brief background of the research topic - exploring the experiences of South Asian parents with a disabled child.

Purpose of meeting (in-depth interview): to give South Asian parents a chance to talk about having a child with a disability, i.e. feelings, difficulties, concerns etc. A topic guide of areas that I wish to have information about (interview schedule) will be used.

I will give you:
- An information pack
- Put you in touch with relevant organisations if you wish
- Answer any questions you may have to the best of my ability
- This study may help other Asian parents in the future.

Time: meeting should take about 1 to 2 hours.

Future meetings: I am hoping to arrange further meetings to gather more information and to inform you of the study. This can be discussed and confirmed at the end of the meeting.

Use of tape recorder: seek permission to use tape recorder:
- To pay attention to what you are saying and not too taking notes.
- You can turn off the recorder when you wish and also when you don't want something you say to be recorded.
- I will be happy to delete anything you wish and/or to destroy the tape if you wish.
- Tapes will be listened by myself, supervisors, transcribers.

Permission to use recorder: **Yes** **No** **Take notes**

Confidentiality and anonymity: information will be used in the study on need to know basis. I am going to change name(s) so that you cannot be identified easily.

Appendix 6b
Interview procedure

South Asian disabled children/young people Code No.

Introduce: myself, the course, purpose of study and brief background of the research topic:

- explore the experiences of South Asian parents of a disabled child and of services that they can get;
- explore South Asian disabled children and young people's experiences about disability;
- explore what services are provided, how and why. What they think of South Asian parents and children regarding disability.

Purpose of meeting: to give South Asian children and young people a chance to talk about their experiences such as:

- how they view themselves;
- how they view other people and what they in turn think of them;
- what they would like to do in the future
- any other issues that they want to talk about.

I will:

- meet with you only if you agree: **Yes No Maybe Don't know;**
- meet at suitable place and time to you;
- use format that is preferred by you;
- be flexible so that you can stop and pull out anytime you want;
- provide **confidentiality** as far as possible – information will be used on a need to know basis but will act upon issues of harm – I will have to tell someone else but I will do this with you;
- give you another name so other people won't know your name
- put you in touch with relevant organisations if you wish
- answer any questions you may have to the best of my ability
- study may help other South Asian disabled children and young people in the future.

Time: meeting should take about 1 to 2 hours.
Future meetings: I am hoping to arrange further meetings to gather further information. This can be discussed and confirmed at the end of the meeting.

Use of tape recorder and video: seek permission to use tape recorder:

- To pay attention to what you are saying and not too taking notes.
- You can turn off the recorder and video when you wish and also when you don't want something you say to be recorded.
- I will be happy to delete anything you wish and/or to destroy the tapes if you wish.
- Tapes will be listened to and viewed by supervisors, transcribers, myself.

Permission to use recorder: **Yes** **No** **Take notes**
Permission to use video: **Yes** **No** **Don't know**

Appendix 6c
Interview Procedure

Service Providers

Introduction:
Pratima Patel – DMU. I am conducting a PhD study regarding the experiences of South Asian parents of a disabled child. This research includes seeking views from Asian parents, children and young people as well as organisations. A range of organisations such as statutory, voluntary and community organisations have been selected from various lists and directories, including your organisation.

Purpose of the research: To find out the experiences of South Asian parents of having a disabled child and also those of their disabled child, as well as finding out the services that are available. This research is intended to add to existing research regarding South Asian disabled children and families, which is limited.

How: Telephone interviews.

When: the interviews will be conducted between January and February this year.

Duration: The interview would be conducted by telephone and is likely to last between half an hour to an hour.

Confidentiality: will be offered in terms of using information on needs to know basis.

Anonymity: will be offered as far as possible.

Would it possible for me to interview yourself or a representative from your organisation – member of the staff team?

I will confirm this in writing.

Date and time of telephone interview:

Thank you very much for your co-operation.

Appendix 7a

Disability and Difference: The experiences of South Asian disabled children/young people and their parents and their access to service provision

Summary – *South Asian Parents*

What is this study about?

- The experiences of South Asian parents with disabled children and *how they get services.*
- The experiences of South Asian disabled children and young people.
- What the people who work in these services think about South Asian disabled children and their parents.

Why was the study carried out?

- There is not a lot of information about what South Asian disabled children and young people and their parents think about their lives and the services that they get, and any difficulties that they might have.
- If services know about what the parents think is good and what can be better it could help them to make the services better.

Who took part?

- 7 South Asian disabled children and young people. I met with them to talk about their lives and videotaped these meetings.
- 11 South Asian parents. I met with the parents to talk about their experiences of having a disabled child and what they thought about services that they got and would like to get. The parents helped in the meetings with their disabled children. They also helped to plan the fun morning for their disabled and non-disabled children, and a group meeting with them (parents). In the group meeting, the parents confirmed the findings of what they had said to me about their *experiences.*
- 22 people from services. I talked on the telephone to the people who give services about what they offer to disabled children, adults and/or to Black and South Asian people.

What did I find?

- Most people in society, the parents and people who work in services thought that disabled people could not do things that non-disabled people could do. Disabled people need to change to be like non-disabled people through medical treatment and/or specialist services *for disabled people.* Disabled people also need looking after. This is what is called the medical model of disability.

- There is also the Social Model of Disability, which most people in society, the parents and people who work in services knew little about. The Social Model of Disability says that it is not the person's disability that stops them from doing things that non-disabled do, but it is the way that other people treat them that stops them from doing those things.

The Social Model of Disability says that it is the way other people treat disabled people that needs to change. Disabled people should be allowed to make choices and decisions, and to do things non-disabled people do. Buildings need to be changed to make it easier for disabled people to use them.

South Asian parents

- It was hard for the parents to look after their disabled children because they had little information about their children's impairments, services and their children's future.
- Most of the parents did not know about the help that they could get from services and about legislation such as the Disability Discrimination Act 1995, and Special Educational Needs and Disability Act 2001, which is important to them and their disabled children.
- Going out and meeting other people in their own communities and the wider society was difficult because other people stared at the disabled children/young people and their parents. They found that places in which other people meet were not easy to get to and that other people did not help them with looking after their disabled children. So, some of the parents did not want to meet with other people in their own communities and society.
- Some of the parents helped their disabled children with personal care, but all the parents looked after their disabled children all the time. This is because they were worried about their disabled children's safety and they made sure that their disabled children were looked after all the time and did not have a lot of time for doing other things.
- Most of the parents did not know about disability before having a disabled child. So they agreed with what the professionals told them about their children's diagnosis and how their impairments could be made better through medical treatment and/or specialist services.
- The parents hoped that their children's impairments would get better in the future, so that they would be able to look after themselves (like non-disabled children).
- The parents were worried about who was going to look after their disabled children in the future when they were not there.

South Asian disabled children and young people

- Most of the disabled children and young people knew that they were treated differently (they were stared at and/or called names) but not all knew that this was because of disability.
- Some of the disabled children and young people did not want to mix with other children and people.
- The disabled children did not have a lot of chances to mix and make friends with other children in different places. Children who went to special schools were supervised at school and at home. They did not have a lot of friends outside school and spent a lot of their time with adults.
- Two of the disabled young people were bullied, but not all talked about this, which could be because they

did not know what bullying was and what to do if they were bullied. It could also be because even if they told someone that they were being bullied, it might not make it better.

- Only one disabled young person talked about marriage. Some of the parents thought that their disabled children might not understand what marriage is about and therefore might not marry. Finding out what the disabled young people think about marriage and what information they need, would help to give them information that they want about this issue.
- Most of the disabled children and young people wanted to go to college, University, work and/or travel in the future. They might find it difficult to do this, because sometimes they do not get a lot of help with their education. Some parents and teachers also think that disabled children would not be able to go to college, University and/or work.
- Some of the disabled young people wanted to be like non-disabled young people because non-disabled young people can make choices and decisions in their lives, which some disabled people are not allowed to do.

Services

- The services that took part in this study knew about the difficulties that South Asian disabled people and their carers have in getting services. They were trying to make their services better but more needs to be done.
- Information in South Asian languages and interpreters was not planned in most of the services. Some services wanted South Asian users who wanted translated information and interpreters to ask for this, but to do this they would need to know about the service in the first place.
- Services that had Black and South Asian people workers had more Black and South Asian people using the services
- Services for disabled people and services for Black and South Asian people did not meet the needs of Black and South Asian disabled people and their carers, who experienced difficulties, because of both disability and racism. This is because disability services worked with disability issues only. Services for Black and South Asian people worked with ethnicity and not with disability issues.
- Services gave information to South Asian people through places in which they meet such as religious places and events. This helped to give information to South Asian people, but the disabled South Asian people and their carers might not be able to get this directly. This is because they might not go to these places because they are stared at, not helped and some places are not easy to get to.
- Some services gave information directly to South Asian people through workers who met with them to tell them about the services and how to get the services. These services had a lot more South Asian people using the services.

What could be done?

- Service providers could give information to South Asian disabled children and their parents directly through workers who could meet with them to tell them about services, how to get these and also about legislation that is relevant to them. This could help the South Asian disabled children and young people and their parents to know about their rights to get services that they need and want.
- Services and groups of Black and South Asian people and disabled people could tell people in their communities about the rights of disabled people and their families to use and get services in their own communities and other services that are used by non-disabled people.
- Services and groups of disabled people should give services that Black and South Asian disabled children and their families want.
- Workers in disability organisations, services and Black and South Asian communities could work together (to share what they know about disability and/or racism) to give information about their services to South Asian disabled people and their families.
- Disabled people and their organisations could work with national bodies such as Disability Rights Commission, Commission for Racial Equality and Equal Opportunities Commission to tell other people in society about disability and racism. They could also advise national policy regarding children and families to make sure that needs of Black and South Asian disabled people are met at a local level.

How to get the full study?

The study will be in the Kimberlin library at De Montfort University, Leicester.

Thanks

I would like to thank:

- The South Asian disabled children and young people, their parents and people who give services for taking part in this study.
- The people who work in services for disabled children who told the parents about this study and thereby encourage the parents and their disabled children to take part.
- Everyone who has helped me with this study.
- The Multi-Agency Disabled Children's Co-ordination Project (Leicester City Council) and De Montfort University for helping to carry out this PhD study.

The study was carried out by Pratima Patel, De Montfort University, Leicester.
1998 - March 2004.

Disability and Difference:

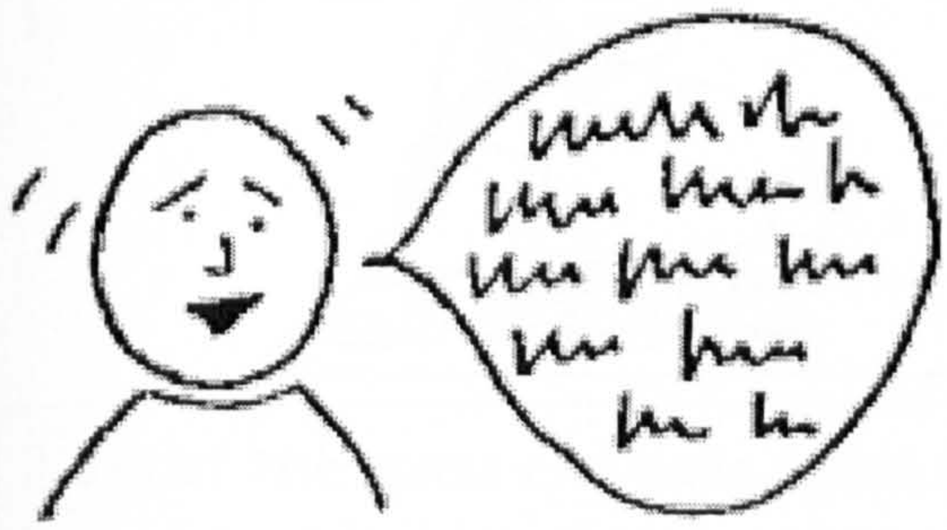
The experiences of South Asian disabled children/young people and their parents and their access to service provision

Why did we talk to you, your mum and dad, and some of the people who help you?

To find out what you like and don't like in your life...

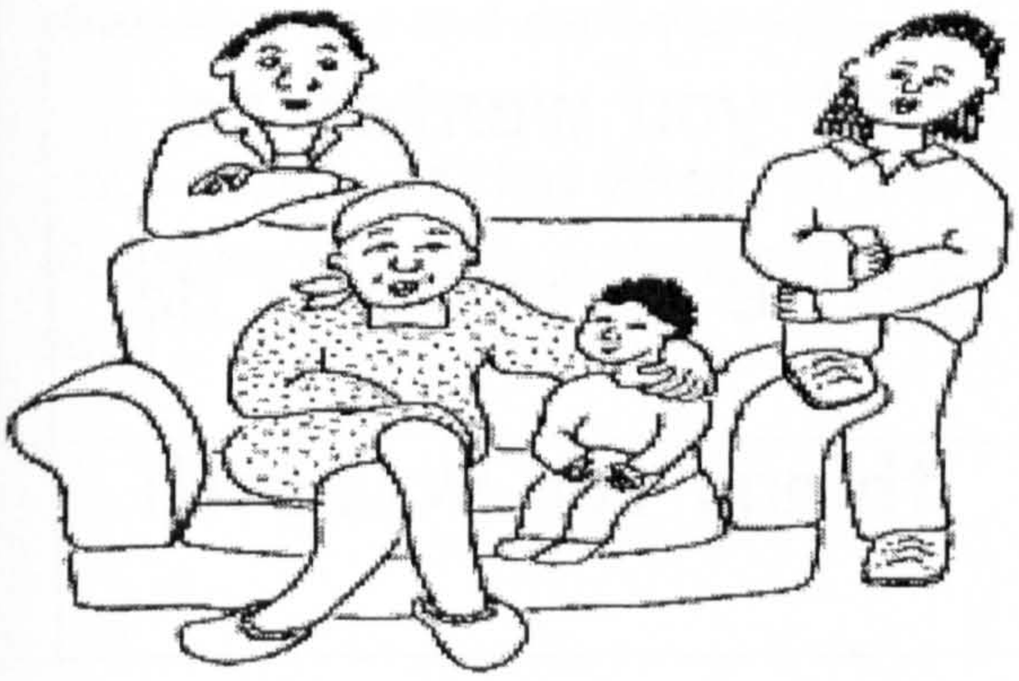
To find out about the help that you and your mum and dad get...

To find out what the people who help you feel as well.



So we can tell the people who help you what you like and what you don't like...

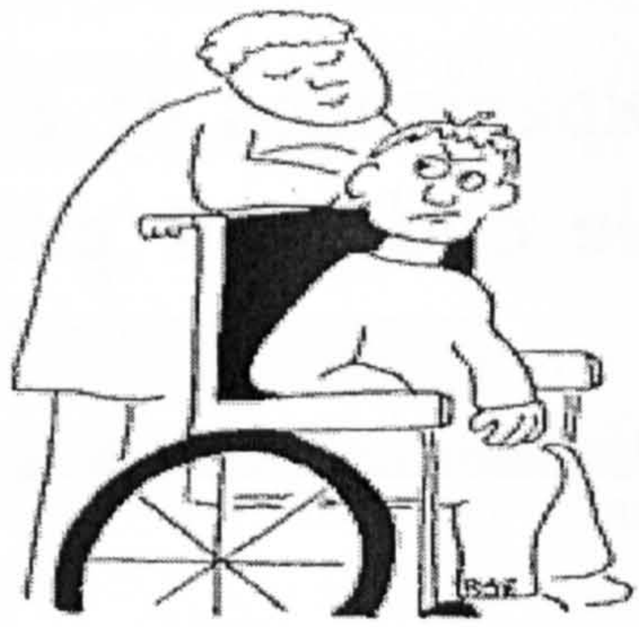
...to make things better for you.



What YOU and the other young people told us

Some of you felt you were treated differently by other people because of disability...

...some of you didn't like to play with other children because of this.



Some of you told us that other children were not nice to you...

...lots of you found it hard to make new friends, in school and out of school.

Lots of you wanted to go to **UNIVERSITY** or **WORK** or to **TRAVEL** when you are older!

Most of you didn't talk about getting married when you grew up!

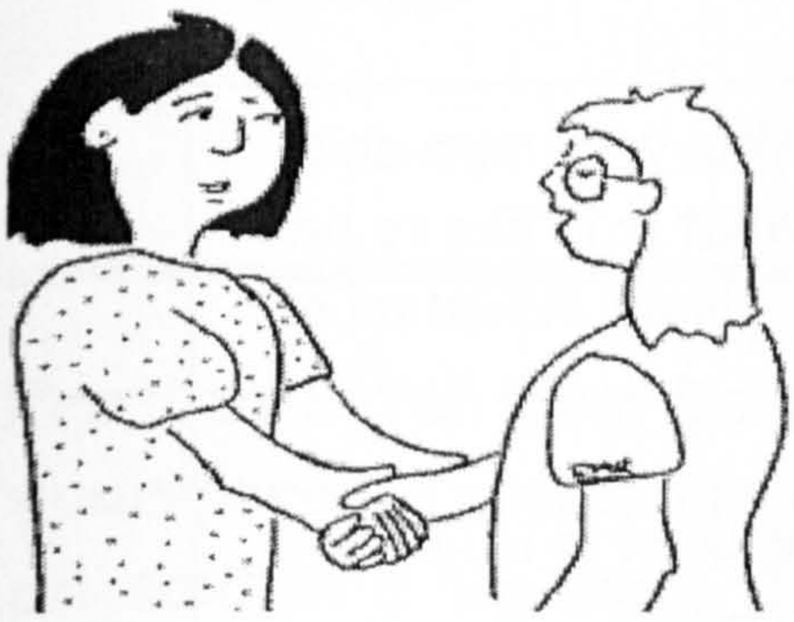
Lots of you wanted to choose things and do things for yourself!

What your mum and dad told us

Lots of the mums and dads did not get a lot of information about the people who could help you...

... like people at school and hospital...

...and about what you could do when you are older!



Lots of mums and dads found it hard to meet other people outside their homes...

...lots of mums and dads did not know about how to get help to make things better for you.

Lots of the mums and dads spent a lot of time looking after you because they love you and care for you...

...but they hope that when you are older you'll be able to look after your self!

What the people who help you told us

We spoke to some of the people who help you, your mum and dad, like people in school, people at home...

Some people said that you and your family sometimes did not get all the help you wanted...

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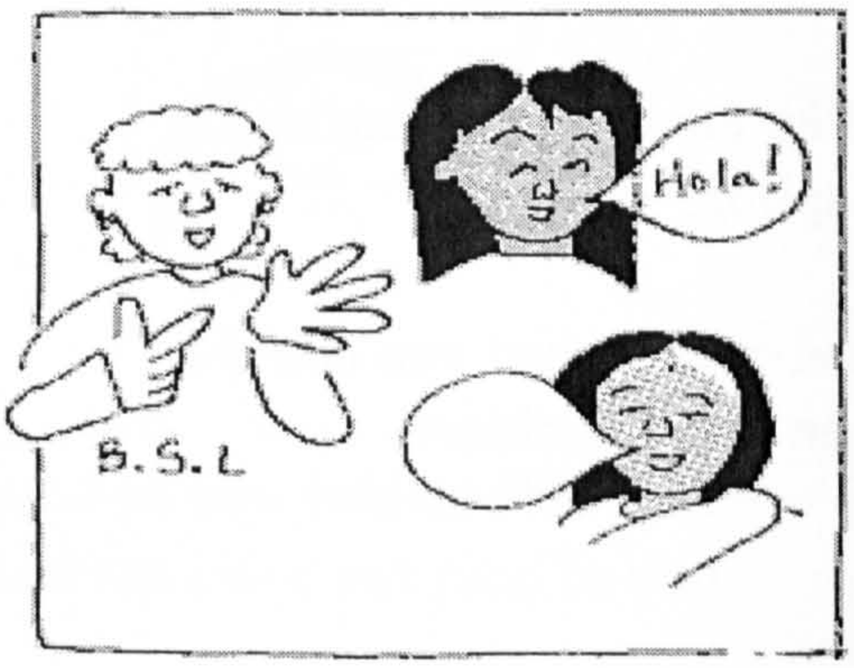


Lots of people who help you, your mum and dad did not know about what it is like to be South Asian (like Indian, Hindu, Pakistani or Muslim)...

Some people did not know what it is like to be helped because of disability.

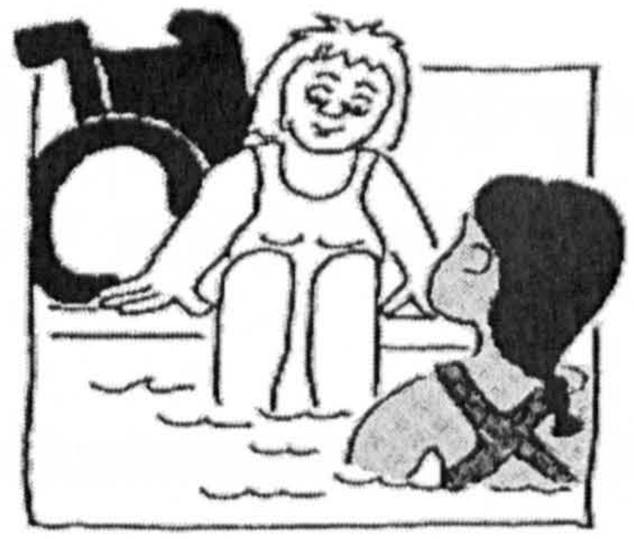
We think that by making it easier for you and other disabled children to go to places like school, clubs, swimming, cinemas...

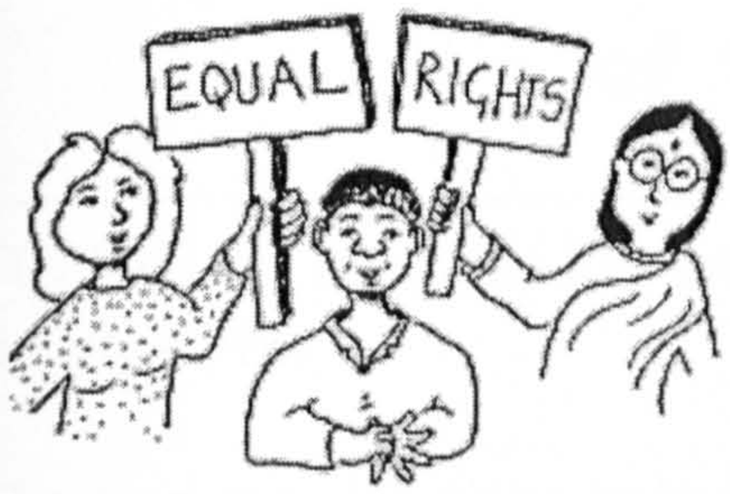
...and changing how people think about disabled children...

...this will let you do the same things that other children and people do!

How things could be made better?

By making it easier for you and your family to find out about the help you can get...





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- All the people who have helped me.
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1998 – March 2004.

Appendix 7b
Summary

Disability and Difference:

The experiences of South Asian disabled children/young people and their parents and their access to service provision

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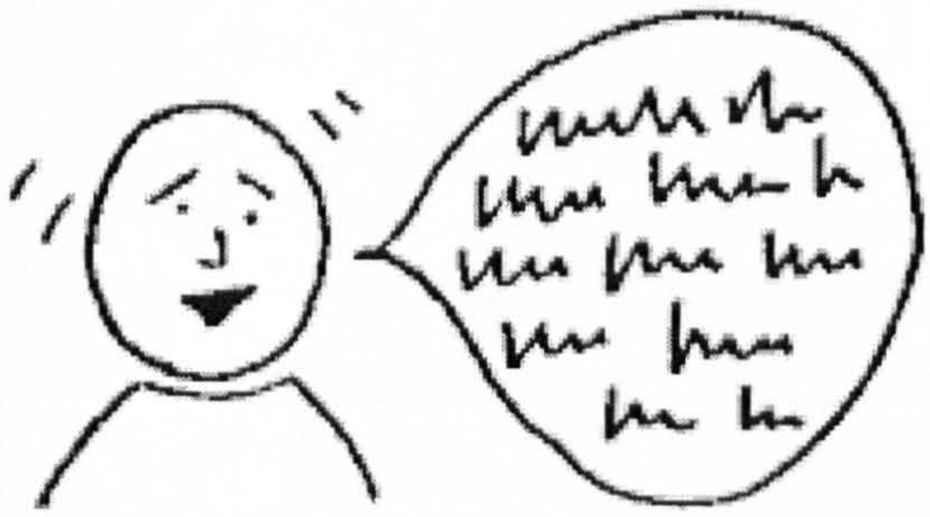

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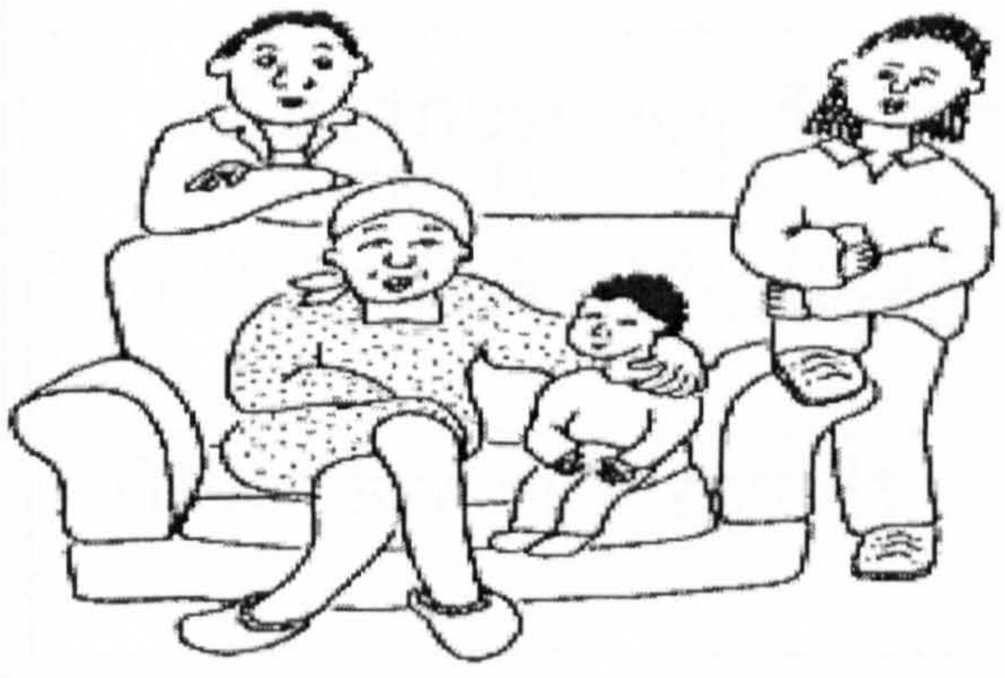

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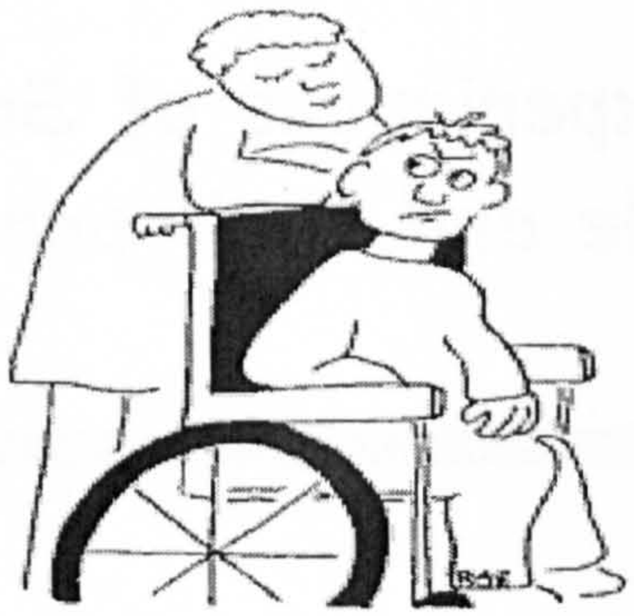

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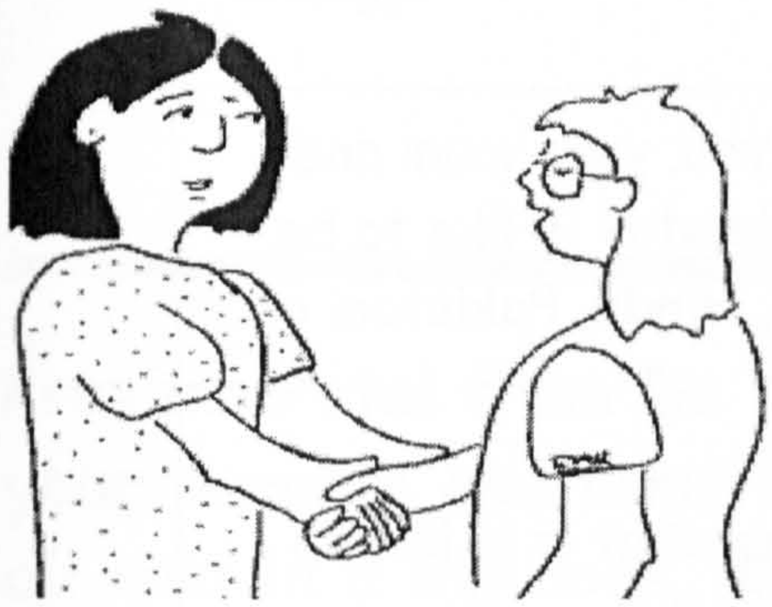

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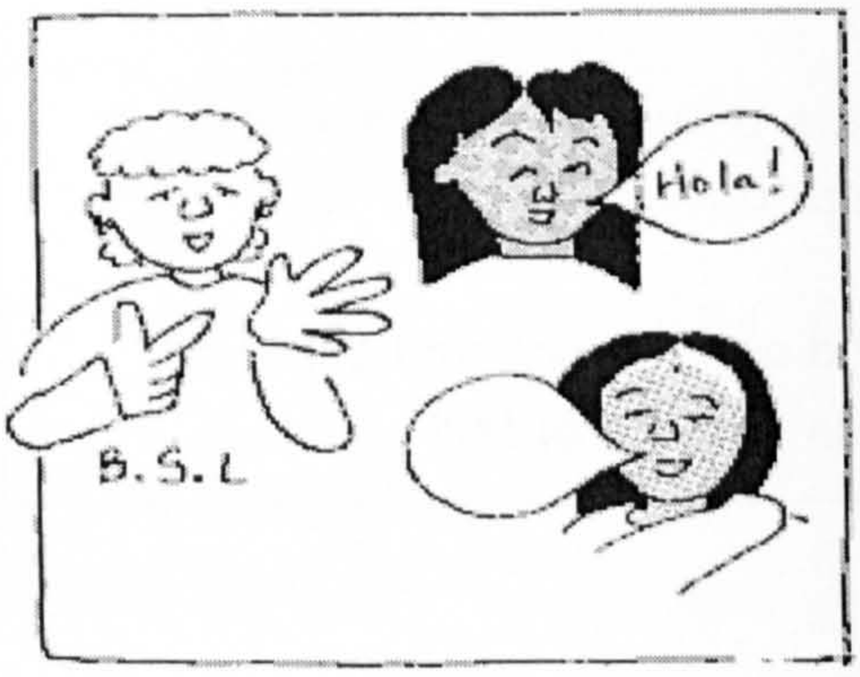

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Appendix 7b
Summary

How things could be made better?

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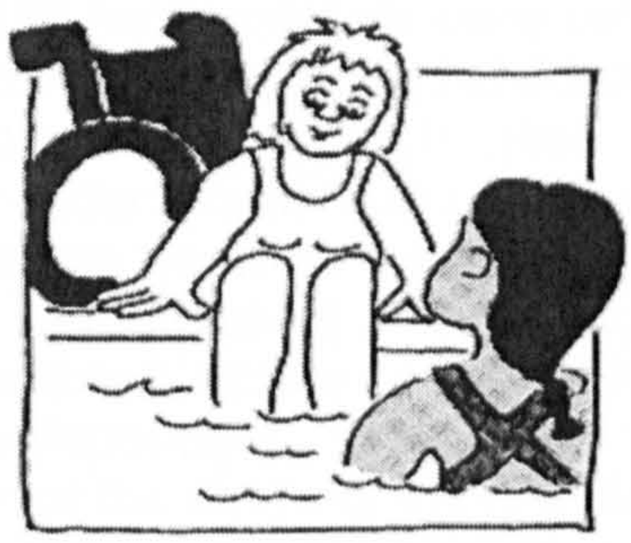

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1998 – March 2004.

Appendix 7c

Disability and Difference: The experiences of South Asian disabled children/young people and their parents and their access to service provision

EXECUTIVE SUMMARY – SERVICE PROVIDERS

Introduction

The aims of the study were:

- To explore the experiences of South Asian parents of disabled children, including their access to services provided by statutory and voluntary organisations
- To explore the experiences of South Asian disabled children and young people
- To explore service provision for South Asian parents of disabled children and young people, and how service providers perceive South Asian disabled children and their parents.

This qualitative study was conducted because there is a need for more focused information about the experiences of South Asian disabled children, young people and their families with regard to the services that they receive. This information is essential to inform policy and planning of services that meet their needs.

The geographical area covered by the study was six Local Authorities in England and comprised City and County Councils.

Participants and methods

The interview was the main method of data collection and allowed the participants to give personal (and/or professional) accounts of their experiences.

- *Seven* South Asian disabled children/young people (aged between 7-18 years) participated in semi-structured interviews, which were videotaped. Some were interviewed more than once. The disabled children/young people had a wide range of disabilities including sensory, physical, and cognitive and communication difficulties.
- *Eleven* South Asian parents of disabled children participated in semi-structured in-depth interviews. The majority, were interviewed more than once. The parents assisted with the data collection with their disabled children, planning the fun morning and the parental group interview. In the group interview the initial findings from the parental interviews were validated before the findings were analysed and written.
- *Twenty-two* service providers from statutory and voluntary sectors, including community groups participated in telephone interviews.

Contact

The South Asian parents were contacted through key services. The disabled children/young people were contacted through their parents. The interdependent relationship that exists in some South Asian families was recognised and the parents were involved in the design of the study, which enabled access to their disabled children. An interdependent model that promotes the inclusion of the views of the disabled children, the parents and the service providers is suggested in providing services that meet the children and their parents' needs.

In general, direct methods yielded more participants than indirect methods.

Findings

The concept of the Social Model of Disability was used to examine the interaction between South Asian parents, the service providers and the South Asian disabled children/young people.

Models of interaction

The findings suggest that the medical model of disability determined the interaction between these three groups. Society's treatment of the South Asian disabled children/young people and their parents also illustrated the use of the medical model, despite an increased awareness of the Social Model of Disability both within society and service provision.

The Social Model provides a conceptual framework, which helps to explain the treatment of disabled people in society and to identify the social barriers that exclude disabled people from mainstream life. Therefore social barriers that are experienced by disabled people need changing.

The medical model promotes a notion of disability that views disabled people as individuals who require correction and/or care through medical treatment and/or rehabilitation, to be like non-disabled people. Disability is seen as undesirable and a tragedy because it is seen as a deficiency and therefore the individual's capability for self-sufficiency is doubted. The individual, tragedy and rehabilitation models are strongly linked to the medical model, in which the common view is that the disabled individual needs changing.

Information

The parents experienced a lack of access to information, advocacy and legitimate forums to express their concerns. Consequently, through which the parents experienced undue pressure to advocate for services and care for their disabled children themselves.

The service providers were aware of the barriers that South Asian users' experience in accessing their services and they were attempting to address these. Despite this the barriers persisted because of a lack of commitment by service providers at the outset.

Information provision in languages and formats (other than English and print) was uncoordinated. The provision of translated information and interpreters was inconsistent. Some service providers provided translated information and interpreters upon request. This means that the potential service user would need to know about the service in the first place.

The parents were unaware about services such as Parent Partnership Officers and legislation such as the Disability Discrimination Act 1995 and the Special Educational Needs and Disability Act 2001, which are important to them and their disabled children to exercise their rights.

The strategies that were used by service providers to inform service users about their services, included targeted information campaigns to South Asian communities through places (i.e. religious places) and events at which they congregate. Whilst targeted information campaigns could be effective to inform South Asian communities about services they are not necessarily effective in directly reaching South Asian disabled people. This is because of their reluctance to socialise with other people in their communities and the wider society due to the negative attitudes and inaccessible environments that they encounter. Therefore, they are unlikely to attend the places frequented by their non-disabled peers within their communities and might rely on family and community members to pass on information about services. This could reinforce South Asian disabled people's dependency on other people within their family and community.

Some service providers also used outreach work with Black and Minority Ethnic people. This was more effective because it allowed information to be given directly to the relevant people, which increased the use of their services.

Disabling environments

The parents and their disabled children experienced negative social attitudes and inaccessible buildings and activities in their own communities and the wider society. Consequently, they were reluctant to socialise with people within their own communities and the wider society, which resulted in isolation.

Not all the parents were well supported by members of their families, which refutes the commonly held perception by service providers that South Asian people are supported by their own communities.

Some of the disabled children/young people were aware that they were treated differently (through disabling environments) but not all were aware that this could be because of disability. Some of the disabled children/young people responded to this by isolating themselves from socialising with their peers and other people.

Two disabled young people were bullied, although not all talked about this.

Caring formed a large part of the parents' lives, and whilst some disabled children required assistance with personal care, all the parents supervised their children all of the time. Supervision also helped with protecting their children from their vulnerability to abuse. This however, limited the disabled children's opportunities to socialise and engage in experiential learning with a wider group of children/young people and in a range of settings.

Disabled children who attended special schools and activities spent their time in supervised company both in education and at home. Therefore they had fewer opportunities to make friends outside these settings.

Hope

The parents did not have previous experience of disability and agreed with the professionals' opinions about their disabled children's diagnosis and suggestions of how this could be improved through medical treatment and/or rehabilitation.

The parents hoped that their disabled children's impairments would improve in the future so that they could take care of themselves, like non-disabled young people.

Two of the young people also hoped that their impairment would be cured or improve in the future. This could be because they wanted to be like their non-disabled peers, who were able to make choices and have control over their lives in a way that they were not able to do, because of being defined as disabled.

Future aspirations

The disabled children/young people's aspirations for the future included further and higher education, employment, and travel. However, achieving this is likely to be difficult because of a lack of support and the low expectations of education professionals and parents regarding the ability of disabled children (with complex needs) to achieve their potential.

Only one disabled young people mentioned marriage. The parents of disabled children with complex needs felt that their children might not understand the concept of marriage and were unlikely to get married. South Asian disabled young people's views about marriage (and related issues of sex, contraception, and relationships) requires further investigation to ascertain their need for information to enable them to make informed choices about this aspect of social life.

Institutional discrimination

The service providers used a 'one size fits all' approach, which means that services are designed to meet the needs of the majority. Those users whose needs do not 'fit into' the majority (because they might require services that are culturally appropriate and information in different languages and formats) are marginalised.

Specialist disability services, and Black and Minority Ethnic services focused on disability and ethnicity respectively, but not on both. This meant that the needs of Black and Minority Ethnic disabled children and their families that arise from both disability and racism were not being met.

However, one service provider addressed the issue of disability and ethnicity, which shows that it is possible.

Black and Minority Ethnic staff in specialist disability services enabled an increase in the use of services by Black and Minority Ethnic service users.

Black and Minority Ethnic services were more likely to provide culturally appropriate services although not necessarily disability sensitive ones. This is because of their implicit knowledge of racism and the needs of Black and Ethnic Minority communities, but not necessarily about disability issues.

Conclusion

The medical model determined the lives of the South Asian parents and their disabled children, despite an increased awareness of the Social Model of Disability at service provider level.

Whilst the service providers were aware of the barriers that are experienced by Black Minority Ethnic and South Asian communities, and they were attempting to address these, the barriers remained. This was because of the lack of commitment at the policy and planning levels.

The parents' ability to advocate effectively for services and to care for their disabled children was restricted, because of a lack of access to appropriate information regarding their children's impairments, services that are available and their children's future. The failure to inform the parents about relevant services and legislation that is important to them and their disabled children denies them the right to full citizenship.

Recommendations

Strategic Direction

- There is a need for a national policy for children and families to provide a strategic direction to address the needs of children and their carers arising out of disability and racial discrimination. The Commission for Racial Equality (CRE), Disability Rights Commission (DRC) and Equal Opportunities Commission (EOC) should work together to promote the inclusion of Black and Minority Ethnic disabled children and their families.

The recent government proposal to merge the CRE, DRC and EOC should provide the opportunity for the new body (Commission for Equality and Human Rights – provisional name) to advise on national policy.

- Disabled people and their organisations along with equality officers within disability services and local authorities are well placed to inform the above mentioned bodies about local needs arising out of disability and racial discrimination. A clear and formal channel of communication needs to be established between the service users (Black and Minority Ethnic disabled users), disabled people's organisations, Black and Ethnic Minority groups and the CRE, DRC and EOC, in which communication can flow through these groups to inform national and local policy.
- The Children's Trusts should provide the opportunity for the formation of multi-agency teams and to promote multi-disciplinary working practices.

Direct communication: outreach work

- Service providers should market their services through direct communication such as outreach work to South Asian disabled children and their parents, because this is a more effective way of informing them about services.
- There is a need for networking to be established between disabled people, their organisations, specialist services such as disability, and Black and Minority Ethnic services. This should enable access to information, knowledge and expertise, to make their services disability and culturally sensitive.

A community development approach to raising awareness

- All workers who work within an equal opportunity policy framework should raise awareness about disability and racism, and the impact of disadvantage on service users in team meetings, supervision and policy forums, as a means of improving policy and provision. These workers should be provided with support, training and networking opportunities to broaden their knowledge.
- Awareness campaigns regarding disability should be led by disabled people and their organisations (national, regional and local) because of their knowledge regarding the discrimination that disabled children and adults experience from the perspective of the Social Model of Disability.
- Disabled people's organisations and Black and Minority Ethnic groups should work with both the DRC and the CRE to bring together issues relating to disability and racism at a national policy level.
- Black and Minority Ethnic services with disabled members of their communities and disabled people's organisations should raise awareness regarding disability issues and legislation within their communities. This should include raising the awareness of community (caste/jati and faith) groups and therefore South Asian communities. Raising awareness of community group members at a national level, through associations (such as the National Council of Hindu Temples (UK), The Muslim Council Of Britain and The Network of Sikh Organisations (UK)) should help to make community groups more inclusive to Black and Minority Ethnic disabled people and their carers.

How to access the full study

The study is located in the Kimberlin library at De Montfort University, Leicester.

Acknowledgement

I would like to thank:

- The South Asian disabled children/young people, their parents and service providers for participating in this study.
- The South Asian parents for their involvement in this study and enabling me to interview their disabled children (as relevant).
- All the service providers, colleagues, friends, family and people who have supported me to conduct and complete this study.
- The Multi-Agency Disabled Children's Co-ordination Project (Leicester City Council) and De Montfort University for their support to conduct and complete this study.

Pratima Patel, De Montfort University, Leicester conducted this study.
1998 - March 2004.

Appendix 8
Topic areas/questions

South Asian disabled children and young people

1 How would you describe yourself?
- tell me a little bit about your self
- what you like
- what you don't like
- what makes you happy
- what makes you sad
- what makes you angry

2 How would you describe other people?
- Tell me a bit about who you like and why?
- Your mum
- Your dad
- Your sisters and brothers
- Your relatives
- Your friends
- Your teachers, doctors
- People who help you

2a Do you think these people like you?
- what do they like about you?
- What don't they like about you?

3 Tell me about what you would like to do when you grow up?
- do you want to go to university
- do you want to get a job and earn money
- do you want to go see places?

4 *Tell me anything* else that I have not asked you?
- what you like
- what you don't like
- what is important to you

5 If you could make a wish – what would this be?

6 If you could change anything in your life
- what would you like to change?

Appendix 9a
1st Interview schedule – South Asian parents

1 Confidentiality

2 Anonymity: change your name (+child's/family's name) to hide your identity. Choose another name (pseudonym).....

3 How did you find out about the study?

4 How did you find out that your child has a Visual Impairment?

-when
-does any one else in the family have this condition? – Genetic?

5 About Information at time of diagnosis

- told of the condition
-told about how to deal with this, any medication, cure, support services
-how
-medium – tape, etc.
-Asian language(s)
-interpreter
-any other information
-referral

6 Has finding out about your child's Visual Impairment made any changes to your life?

-how you feel
-how your family, friends, relatives feel
-support
-how you/your child is viewed by other people

7 What are your hopes about your child's future?

-hopes/aspirations
-concerns

8 Do you get any help from organisations such as education, health, social services etc.

-what help do you get
-from which organisation(s)
-what does this organisation(s) do
-what else do they offer
-what right do you feel you have to this help
-do you have any difficulties, concerns
-are your cultural needs i.e. language, dietary, etc., needs being met
-useful – how/what
-not useful – how/what-Improvement – how/why

re:education did VI teacher tell of what to at home?

(continued)

Details of interviewee

Name: Parent/Guardian:

Address:

Telephone:

Background:

Languages: Bengali Gujarati Hindi Punjabi Urdu Other

Spoken.....Read.....Written.....

Details of child(ren)

Name: M/F

Visual Impairment (condition) if known.....not known.....
Multiple Disabilities Visual Impairment (condition) if known.....not known.....

DOB.....or age(s)

Pre-school☐ Primary☐ Secondary☐ FE☐ Other☐

Mainstream.....Special.....

Details of family members
Children
M/F
Visual Impairment
Multiple disabilities and Visual Impairment
Disability
Extended family
Age

Any other comments

Information pack	Yes	N
Future meeting(s)	Yes	No
Arrangement for next meeting		
Presentation: to tell you about findings before study is written	Yes	No
Summary of completed study to be sent?	Yes	No
Access to completed full study	Yes	No

Thank you very much for giving the time to talk to me.

(continued)

Which organisations listed below were used?

Education – VI team

Social Services – VI disability

Social worker

Health

Community group(s)

Local support group(s)

Local Society for the Blind

RNIB

Religious organisation(s)

Other

Appendix 9b

2nd interview questions – South Asian parents

Date: **Code:**

1 **Length of time for diagnosis: confirm this.**
- How much did parents have to push for their child to be diagnosed?

2 **How did you find the approach of the doctor and medical staff to informing you of your child's condition etc.**
- terms used
- sensitive, friendly etc.
- background of the optician, doctor, etc.
- did you know who the people who diagnosed your child were?

3 **In our last meeting we talked about your feelings such as .....when you found out about your child's condition.**
- How did you deal with this?
- what did you do/

4 **Family and friends being supportive was also mentioned?**
- how did your family support you
- what did they do
- what did you find most useful
- who did they support you, your child or both
- what did your friends do
- what did they say
- who did they support you, your child or both

5 **Caring - who does this?**
- How?
- are you aware of Respite care
- do you use this
- Would you use this?
- What do you think of respite care?

6 **If you were given a choice about information**
- What information would you want to support your child?
- How would you want this information
- who should give this

6a **Would you want information for yourself**
- What kind of information would you need

Appendix 9b

2nd interview questions – South Asian parents

6b Do you think your child needs information?

- To understand their condition
- To deal with this etc.
- who should give this
- how

7 Is your child registered Partially Sighted or Blind?

Yes ☐ No ☐ Don't Know ☐

8 Does your child have a Special Education Need statement?

Yes ☐ No ☐ Don't Know ☐ Going through Process ☐

- Do you know what this is?
- Have you been given information about this?
- Do you know of named persons/parent partnership officers

9 How does your child get on with:

- Brothers/ sisters
- Relatives/ friends
- Teachers/ social worker/ medical staff
- Neighbour/ other people

10 Can you tell me a little bit about your child?

- what does s/he like to do

11 This question is about community and religious organisations.

A What do community organisations do?
- why don't you use these?

B What do religious organisations do?
- do you and your child go to these
- what do you do
- how do they support you and/or you child

Before I finish, I would like your views on disability, it is not about yourself, but you generally think about disability.

Appendix 9b

2nd interview questions – South Asian parents

12 Views and thoughts

1 In these pictures which children/young people do you think has a disability?

2 Which of the following, do you think disabled children can take part in:

a. school – mainstream/special

b. shopping – on their own/ with other people

c. leisure activities - cinemas, swimming, play with other children in the neighbourhood

d. cultural activities – celebrations, community functions and plays, outings, weddings, family gatherings, language classes

e. religious activities – festivals, prayers, religious classes

f. training

g. work/employment

h. have a relationship/ be married

i. have children

j. look after themselves/be independent

3 Which other activities can they do?

4 Which can't they do?

5 What do you think are the positive aspects of having a child with a disability?

6 What do parents have to think about when they have a child with a disability?

7 Any other comments.

Thank you

i. Information pack: given ☐ not given ☐
ii. Choose information from additional resources: Yes ☐ No ☐
iii. Future meeting – usefulness of information Yes ☐ No ☐
iv. Asian parents will be contacted in due course regarding Asian parents meeting – initial findings.

Appendix 10

Telephone Interview Questions - service providers

Details (collected at initial telephone conversation)
Name
Position/Job title
Organisation
Contact details

Tel:

Location:

Date:

Interview:
Telephone interview (noted by researcher) ☐
Face-to-face interview ☐
Group/workshop ☐

(continued)

1 Services offered

As mentioned during our previous conversation, my interest is in disabled children and families from Ethnic Minority (EM) communities, particularly, South Asian communities.

If YES to service provision to disabled people carry on;
If NO to go to questions 2

Could you please tell me what services you offer to this group of people?

Prompts:
What, how, when, where
Any different
Disabled people
Carers
EM/A disabled people
E/M carers

1a Could you please describe how services are offered?

Medical model
Social model

1b Could you please tell me how the people who use your services are informed.

What, how, where
Translated info
Interpreters
Local communities
Local org.
EM/A orgs

1c Could you please tell me how users of your services access your services/organisation.

What, how, where

(continued)

1d In terms of services that offer support in the home:

- How many providers who provide support in the home are there in the area (cb)?
- Is there a mix of ethnic groups of these providers (cb)?

2 If you were able to offer services to disabled people/children and/or Ethnic minority/Asian disabled people/children, what could your service offer?

What, how
Why
Barriers

3 **Service provision for Ethnic Minority and Asian communities**

In terms of offering services to Ethnic Minority/Asian users of services, what do you think are the issues involved in providing services that are appropriate to these communities?

- In what way are your services appropriate?

(continued)

3a Do you think that Ethnic Minority *and Asian users* of services, use the full range of services that are offered?

3b Research shows that service providers are concerned about the low take up of services by Ethnic Minority and Asian users of service – What is the experience regarding take up of your services?

4 Breakdown of users of services?

Could you please provide me information about the number of people who use your services/organisation regarding:

Number (most recent figures)	Total	Gender F M	Ages
How many people use your services/organisation			
How many disabled people use your services/organisation			
How many EM/Asian people use your services/organisation			
How many disabled EM/Asian people use the services/organisation			

4a Is the gender of the users of your services monitored?

(continued)

5 **Breakdown of Staff**

Could you please provide information of the ethnic background and gender of your staff team?

- Would you mind telling me your ethnic background?

White	**F**	**M**
British		
Irish		
Any other white background		

Mixed	F	M
White and Black Caribbean		
White and Black African		
White and Asian		
Any other Mixed background		

Asian or Asian British	F	M
Indian		
Pakistani		
Bangladeshi		
Any other Asian background		
Black or Black British		
Caribbean		
African		
Any other Black background		

Chinese or other ethnic group	F	**M**
Chinese		
Any other		

(continued)

6 Policies

Regarding the Disability Discrimination Act 1995 and Part 3 – goods, facilities and service.

Have there been any changes to your services and organisation since this came into force?

6b In terms of Equal Opportunity, may I have copy of your Equal Opportunity statement and/or policy?

Yes No Don't Know Received/Not received

7 Personal

What brought you into this kind of work

- Working with disabled people
- Working with EM/Asian communities

8 Have you got any comments regarding /Asian parents of a disabled child?

Thank you for your time and co-operation.

Appendix 11
Letter inviting service providers to participate

Dear

Re: PhD study

I am conducting a PhD study, at De Montfort University, which explores the experiences of Asian parents of having a disabled child. The sample comprises Asian parents of a disabled child, disabled Asian children and young people, and service providers.

My field experience, as a practitioner, includes working with Ethnic minority/Asian communities and disabled children and their families. I have found that there is lack of information regarding the experiences of Asian parents of a disabled child and that of Asian disabled children and young people. This study intends to contribute information to increase the understanding that professionals and practitioners have regarding the experiences of Asian disabled children and young people, and their parents/families, with a view of improving policy and practice.

To gain a picture of the services that are available and the approaches that are used to deliver services a range of relevant services and organisations (statutory, voluntary and community) have been selected, which include your organisation.

I am intending to conduct telephone interviews during March. The interview should take approximately 30 minutes and is confidential. Interview questions will be about: services that are offered; service provision for Asian disabled children/people and their families/carers; statistical information regarding users of services and staff, and policies.

This letter will be followed by a telephone phone call in the near future to request participation from yourself or a representative from your organisation, which will be greatly appreciated. If you have any questions please call me at **0116 207 8760**, e-mail ppatel@dmu.ac.uk

Yours Sincerely

Pratima Patel